The Impact of Schizophrenia on Patients and Key Relatives: A Social Cognitive Approach.

DÓNAL GERARD FORTUNE
B.Sc. (Hons), Ph.D.

Thesis submitted in partial fulfilment of the requirements for the degree of
Doctor of Clinical Psychology

University of Warwick, Department of Psychology,
and Coventry University, School of Health and Social Sciences
May 2002

Table of Contents

List of Tables

List of Figures

Acknowledgements

I would like to thank the participants who took part in the studies that make up this thesis, and indeed without whom there would be no thesis. I am indebted to people who actively helped in identifying potential participants especially Marion Bailey, St. Anne's Orchard, Malvern, Andrea Halse, National Schizophrenia Fellowship, Bromsgrove, and Dr. Ruth Sheen, Kidderminster General Hospital. I would also like to thank Bernie Campbell, and Dr. Dominic Markham for their helpful feedback on the protocol for Warwickshire, for access to mental health meetings, and for aiding with recruitment, and also to Mary McGorry, CMHT manager, who helped with access to community teams in Warwickshire and recruitment.

I am grateful to Professor Rona Moss-Morris, Auckland University School of Medicine, for permission to use the pre-publication IPQ-R.

Special thanks to my supervisors Dr. Kay Garvey and Dr. Jo Smith for their inspiration, perspiration, and unhesitating support and confidence in the projects that make up this thesis.

Declaration

This thesis was carried out under the supervision of Dr. Kay Garvey and Dr. Jo Smith and is my own work. No portion of the work referred to in this thesis has been submitted in support of an application for another degree or qualification of this or any other university or institute of learning.

Summary

The impact of severe mental illness on the individual and their family can be substantial. In addition to living with the vagaries of a condition that can be of unpredictable duration and severity, individuals and their families may also have to live with public perceptions that can be devaluing, discriminatory or indeed hostile. The purpose of this thesis is to examine the impact of severe mental illness on the individual and their key relatives using a social cognitive perspective. Chapter 1 provides a review of the mechanisms and consequences of stigma and discrimination in severe mental illness, and explores ideas for intervention that are predicated upon empirical research findings. Chapter 2 examines the pattern of desynchrony between lay representations of severe mental illness held by individuals, their carers, and a sample of the general public. It also highlights the association between aspects of perceived stigma and divergent patient-parent representations of schizophrenia. Chapter 3 adopts a self-regulation theory approach to distress in the relatives of people diagnosed with schizophrenia and concludes that aspects of the self-regulation approach, (perceptions of psychosis, coping, and primary appraisals) have some utility as a framework to understand distress in the carers of people diagnosed with schizophrenia. Finally, chapter 4 reflects on the research process and discusses the development and course of the research. It also provides some further reflections by participants on the experience of severe mental illness.

CHAPTER 1

Literature Review

Stigma, Discrimination and Severe Mental Illness: Consequences, Mechanisms, and Interventions.

Abstract

There is a vast literature describing the importance of stigma as a factor in the social exclusion of people diagnosed with severe and enduring mental health problems. Much of the canon of stigma literature comes from diverse areas, making use of a variety of methods with the result that practicing clinicians may not be fully aware of current issues in the literature pertaining to stigma. This paper reviews current psychological understanding of the process of stigma in psychosis, paying particular attention to the social cognitive mechanisms by which stigma may come into being, and the extent of its consequences for patients and their families. Given the importance of the social environment to outcome in psychosis, studies will also be reviewed that have addressed the attitudes of healthcare professionals towards people diagnosed with psychotic illnesses and will briefly review studies relating to social cognitive aspects of family interactions. This review will also critically examine research pertaining to the development of interventions to undermine stigma. It is argued that social cognitive processes, particularly attributions that arise from social cognitive cues in the context of lay or common-sense models of illness, are the principal contributors to stigma, discrimination and social exclusion. The review concludes that interventions based upon psycho-education or consumer group protest are unlikely to be successful in challenging and changing stigmatizing practices on their own. The promotion of social inclusion through public contact with individuals with such diagnoses is likely to be most effective in bringing about lasting and concrete changes in stigma.

Introduction

Over the past half century research has suggested that stigma has long been used as a vehicle to psychologically legitimize and permit a range of discriminatory practices against those who are deemed to possess a discreditable, feared or socially unacceptable feature that sets them apart from those without such a manifest 'mark' (Goffman, 1963; Nunally, 1961). While stigma has a long history in relation to mental health issues, it is only relatively recently that research has expanded upon the descriptive experiences of stigma to furnish an explication of the psychological processes underpinning stigma, its potential outcomes, and the nature of interventions that might prove helpful in tackling stigma. Legislators have also begun to recognise the importance of stigma and discriminatory practices to the well-being of patients with severe mental illness, and healthcare frameworks have recently been made explicit in this respect (e.g., UKDoH, 1999a; USDHHS, 1999). Moreover, it is becoming apparent that the effective treatment of severe mental illness may be compromised when the stigma that is associated with such diagnoses is not equally as aggressively tackled (Corrigan, 2000; Crisp, Gelder, Rix, Meltzer, & Rowlands, 2000; Link, Struening, Rahav, & Phelan, 1997).

Given the scope and clinical implications of the problem, this paper will provide a review of the psychological and social sequelae of stigma with respect to severe and enduring mental illness. Following an examination of the extent of the problem, an outline of theoretical issues pertaining to person perception in the

social domain will be reviewed with particular reference to the factors influencing public attitudes to persons with psychosis. Next, research on attributions for patients' illness behaviour related to causal and control attributions within the family will be reviewed as potential contributors to stigma. These sections will not be exhaustive, but the main studies which have contributed to our understanding of the role of social cognitive processes in the observers attempt to make sense of the individual and their condition, or which have addressed theoretically or clinically important relations between social cognition and the course or outcome of schizophrenia will be described. Theoretical and practical work on lay theories or common sense models of illness will then be reviewed as they have relevance to 'felt' or perceived stigma. Finally extant research on interventions seeking to challenge and change the practice of stigma and discrimination will be explored. The conclusion will attempt to explicate some of the key questions that are posed for future research.

Definitions of Stigma

Like many other constructs in mental health research, the nature of the definition of stigma shows wide variability in the literature. Stigma has been viewed as one of fifteen elements of empowerment (Chamberlin, 1997), as synonymous with overt discrimination (Byrne, 1997), or as not particularly a problem at all (Gove, 1980). Sayce makes the important point that the terms we use could lead to different understandings of where responsibility lies for the problem and as a

consequence to different prescriptions for action (Sayce, 1998; Sayce 2000). Addressing stigma without also incorporating prejudice and discrimination would thus be likely to place the onus of stigma solely on the stigmatized individual and prevent an adequate explication of the role of others in discriminating, prejudicing and stigmatising people with a diagnosis of severe mental illness (Sayce, 2000; Link, 2001).

In many instances, investigators provide the dictionary definition of stigma, such as "a mark of disgrace or infamy" (Royal College of Psychiatrists, 2000). Stafford and Scott (1986) offer a definition in terms of behavioural transgression of a social norm, while Crocker, Major and Steele (1998), offer that stigmatized individuals are believed to possess "an attribute that conveys a social identity that is devalued in a particular context" (p.505). With regard to adopting a working definition, most investigators turn to the seminal work of Goffman (1963), where stigma is defined as an attribute that is deeply discrediting, reducing the bearer from a whole and usual person to a tainted discounted one. He applied the term to any condition, attribute, trait or behaviour that symbolically marked off the bearer as "culturally unacceptable". This definition has been distilled by Jones, Farina, Hastorf, Markus, Miller, & Scott (1984), into probably the most widely used definition today - as "the relationship between a mark that associates a person with some undesirable characteristic" (p.13) - an attribute that becomes linked to a stereotype.

In addition to stigma that may be enacted upon the individual in the form of discriminatory practices, individuals who have been given a psychiatric diagnosis may perceive the possibility of rejection in their social encounters and thus internalise these stereotypes and beliefs. Thus anticipation of discrimination and rejection - 'felt' stigma - can further add to the individual's difficulties. There is some evidence that felt and enacted stigma may not necessarily be concordant (Wahl, 1999; Corrigan & Watson, 2002).

The Scope of the Problem

Stigma and Discrimination

Examination of the research into enacted stigma shows that three types of discriminatory practice have been observed that directly arise from stigma: direct discrimination, structural discrimination, and discrimination arising from the lay theories and beliefs held by the general public and the stigmatised person. Examples of direct discrimination include members of the public refusing to employ a person with a psychiatric diagnosis, or offer this person the same quality of medical care as would be offered to an individual without such a diagnosis. Structural discrimination refers to the action of stigma upon the structure around the person, leading them to be exposed to an array of untoward circumstances such as positioning of treatment facilities in disadvantaged areas. The third type of discrimination is that which operates through the individual internalising lay theories or common-sense models of disorder, for example,

believing that people with severe mental illness diagnoses will not recover from their illness, or they are responsible for their difficulties (Furnham & Bower, 1992; Warner, 2000).

Effects of Stigma

While the effects of stigma on individuals holding a psychiatric diagnosis are widespread, most of the research has tended to cluster into three main areas: impact on everyday living (housing, employment, and affiliation), psychological distress, and neglect of physical health needs.

Impact on Everyday Living

Research has suggested that employers are less likely to offer employment to individuals who have been given a mental illness label (Bordieri & Drehmer, 1986; Farina & Felner, 1973). In the UK, the Labour Force Survey of 1997/1998 (Office of National Statistics, 1998) showed that persons with a history of psychiatric disorder were three times less likely to return to work when compared with disabled people generally. Importantly, this disparity is not accounted for by inability to work (Sayce 1999). Access to services from life insurance to mortgages have also been shown to be significantly affected by a diagnosis of mental illness (Read & Baker, 1996; Sayce 1998). Similarly, affiliation is also significantly compromised by stigma. Hall and colleagues (Hall, Brockington, Levings, & Murphy, 1993) found that approximately 50% of residents of a rural community would choose not to live next door to a person with a mental illness

diagnosis or permit their children to speak to them. It is unsurprising that the majority of people with a psychiatric diagnosis maintain their illness as a secret (Wahl, 1995; Link Mirotznik, & Cullen, 1991). However, maintaining secrets can create its own pressures and such fear of rejection can promote social withdrawal and psychological distress (Link, et al, 1997). Social withdrawal tends to be a robust predictor of chronicity of psychosis (Eckman, Wirshing, Marder, Liberman, Johnston-Cronk, Zimmermann, & Mintz, 1992; Kay, 1991).

Psychological distress

The positioning of discrimination, exclusion and rejection at the heart of stigma suggests that stigma can be associated with significant psychological distress. In a study of 487 families across 20 different states in the US (Wahl & Harman, 1989), the most frequently cited effects of stigma were on the patient's self esteem, difficulties making and keeping friends, difficulties finding employment and reluctance to disclose mental illness. This 'felt' form of stigma, which involves anticipation of the negative reaction of others, has been shown to lower individual's self esteem (Wright, Gronfein, & Owens, 2000), affect the nature of coping that individuals engage in (Link et al, 1991), and to influence the quality of social interactions with others (Farina, Allen & Saul, 1968; Link, Cullen, Struening, Shrout, & Dohrenwend, 1989), thereby further stigmatising and excluding individuals from society and from access to valuing interpersonal relationships.

The impact on physical health

In addition to its well documented effects on psychological health, stigma has also been linked to a variety of health outcomes ranging from individuals delaying access to health services, to the nature of medical care that will be offered to people with mental illness diagnoses. According to the UKDoH (1994), standardised mortality rates among people with schizophrenia are two and a half times the average and users of mental health services frequently report that they receive late or insufficient tests for physical complaints, often because such complaints are initially interpreted as a manifestation of psychiatric illness (Read & Baker, 1996; Sayce, 2000).

Three large recent studies suggest that there may be some basis for patients' suspicion of the quality of care that is offered. In a study of 113,000 patients treated for myocardial infarction (MI), Druss, Bradford, Rosenheck, Radford, & Krumholz, (2000), compared the type of medical treatment offered to patients who had previously been diagnosed with schizophrenia or depression and that offered to patients without such additional diagnoses. MI patients with a mental illness diagnosis were 28% less likely to undergo catherisation, 25% less likely to undergo angioplasty, and 32% less likely to undergo by-pass surgery than their counterparts. Similarly, this research group subsequently demonstrated that older adults with mental disorders had elevated death rates, and were also less

likely to receive each of five established quality indicators for MI than the general population (Druss, Bradford, Rosenheck, Radford, & Krumholz, 2001). Compared with MI patients without a psychiatric diagnosis, patients holding such diagnoses had a 19% increased risk of dying within 1 year after MI. Wang, Demler & Kessler, (2002) found that patients diagnosed with schizophrenia were significantly less likely to receive adequate treatment (using evidence-based guidelines) than those with less severe disorders such as anxiety. Only 40% of seriously mentally ill patients had received treatment in the past year, and only 39% of these patients had received adequate treatment. Only 1 in 20 people with psychosis had received adequate treatment (Wang, Demler & Kessler, 2002). These findings suggest that a mental illness label may be sufficient to bring about significant discriminatory practices, and that healthcare professionals are not immune to such practices.

Access to effective treatment,

Traditionally, severe and enduring mental illness has attracted less attention and as a consequence, less funding than other disorders such as stroke or learning disabilities (UKNHSE 1996). This discrepancy between the extent of disability and research funding has led to a treatment effectiveness lag, which is now recognised to have been in operation for decades (UKDoH, 2001). Recent initiatives have begun to be set in place to counter this effect although it is too early to judge their potential for success.

Treatment settings

The impact of stigma on access to effective treatment, may result in mental health centres being placed in undesirable settings. While the general trend has been to move acute inpatient facilities from psychiatric hospitals to general hospital settings, the 'not in my backyard' (NIMBY) phenomenon, in which members of the public fight against having treatment facilities or housing in residential areas, is a widespread obstacle to the community integration of people with a mental illness diagnosis (Robert Wood Johnston Foundation, 1990; Sayce, 2000). Lyons, El Sayed, & Mathew (2001) conducted a study in which service users were surveyed as to whether a move from a general hospital to a new psychiatric hospital unit increased their perceptions of stigma. Two thirds of service users found treatment in the new hospital potentially more stigmatising, and only 43% felt the benefits of the new unit outweighed the stigma. McGorry and colleagues (McGorry, Phillips & Yung, 2001), developed a non-stigmatising early intervention service for adolescents which was sited in a young people's health service – the 'centre for adolescent health' - and reported extremely low levels of attrition from the service and significant reductions in distress.

Treatment delay

In the USA, it has been estimated that less than half of those who experience psychological phenomena congruent with symptoms of mental illnesses seek treatment (USDHHS, 1999). In addition, research has demonstrated that patients

and relatives perceptions of stigma associated with severe mental illness can affect their willingness to consult psychiatric services. Higher levels of shame and stigma felt by the relatives of patients subsequently diagnosed with schizophrenia were associated with patients' longer treatment delay (Okazaki 2000). In a study of treatment delay in European versus Chinese caregivers, Ryder, Bean & Dion (2000), found that Chinese caregivers were more affected by the stigma of mental illness and therefore more likely to delay consultation. In a study of women attending a mental health clinic, Alvidrez (1999), reported that the stigma associated with having an additional substance use problem, use of mental health services by family or friends, and the belief that mental illness is caused by an imbalance or lack of moderation in lifestyle/environment were all predictors of poor consulting behaviour.

While the effects of stigma have been fairly well documented, the nature of research findings tends to be somewhat descriptive. There is clearly a need for more experimental and predictive studies as the available literature is limited in its ability to provide more in the way of substantive findings. However, research into the mechanisms by which stigma emerges or leads to discrimination has been more successfully grounded in theory, particularly social cognition and attribution theory, and is consequently better able to address implications for intervention.

Mechanisms of Stigma

Social Cognition

There is broad agreement that perceptions and judgements of people reflect not only objectively available stimulus information, but also to a considerable extent, the observers own inferences or stereotypical expectations (e.g., Fycock & Stangor, 1994). Social cognition refers to two strands of person perception in the social domain: (1) how people make sense of others, and (2) how they make sense of themselves in real world situations. The social cognition approach focuses on individual cognitions such as thoughts and beliefs, as processes that intervene between cues or signals and behavioural responses. These cognitions in turn are modulated by implicit working models of self and others.

Attributions are central to the social cognitive approach and provide a framework for understanding the explanations that individuals give for their own behaviour and the behaviour of others. In everyday conversation it has been estimated that individuals make a causal attribution (a 'because' statement) every few hundred words (Zullow, Oettingen, Peterson, & Seligman, 1988). The need to abstract meaning from often ambiguous situations is at the heart of stigma in so far as our requirement for speed in the processing of information often has a tendency to mean cognitive shortcuts are taken (Macrae, Milne & Bodenhausen, 1994; Lyons & Ziviani, 1995). There are two general biases in social cognition by which such shortcuts can lead to stigmatising reactions towards people with severe and

enduring mental illnesses: the availability heuristic and the representativeness heuristic.

Theoretical Considerations - Heuristics

The Availability Heuristic (Kahneman, Slovic & Tverskey, 1982) refers to our tendency to judge the frequency of an event in terms of how readily we can bring examples of it to mind. The more easily we can think of an instance where a person described as 'schizophrenic' has been reported to have 'run amok', the more frequently we view such an event as actually occurring - we tend to overestimate the relative frequency of such events.

Penn, Kommana, Mansfield, & Link, (1999) investigated whether presentation of information describing the association between violent behavior and schizophrenia could affect participants' impressions of the dangerousness of both a target person with schizophrenia and individuals with mental illness in general. Participants who reported previous contact with individuals with a mental illness rated the male target individual and individuals with mental illness in general, as less dangerous than did participants without previous contact. Participants who received information summarizing the prevalence rates of violent behavior among individuals with schizophrenia and other psychiatric disorders (e.g., substance abuse) rated individuals with a mental illness as less dangerous than did participants who did not receive this information.

Some researchers have also pointed to the deleterious effects of prejudiced portrayal of people with mental illness in the media as contributing to such heuristic effects (Wahl, 1992; Wahl, 1995; Wilson, Nairn, Coverdale & Panapa, 2000; Philo, 1996). Studies of television characters in the 1990's indicated that the majority of mentally ill characters are still portrayed as not only dangerous but also touched with a sense of evil that justifies mistrust (Rovner, 1993; Philo 1994).

The Representativeness Heuristic on the other hand is heavily involved in categorisation processes. If another person seems to possess traits that are 'typical' of persons belonging to some category, we assume that this person too, belongs to this group. The reason that we use such heuristics is that they are remarkably efficient. They permit us to reach valid conclusions about others with a minimum of effort. However, they may also lead to significant bias. In general there are four cues, which are dependent upon the representativeness heuristic, and act as a stigmatizing 'mark' for people with severe mental illness - labeling, symptoms, deficits in social skills, and physical appearance.

Labeling

Much has been written about the impact of labeling people with psychosis with unhelpful politically incorrect and stereotype-inducing forms of descriptions. People who are given the label of mentally ill tend to have less income and are more likely to be underemployed compared to a similarly impaired but unlabeled

group (Link, 1982), and this effect remains evident even in the absence of the person's unusual behaviour (Link, 1987).

There has been a move towards adopting more politically correct labels to describe people with mental health difficulties often as a result of protest campaigns instigated by service user groups. The label "consumer of mental health services" is widely regarded as a term that is more likely to empower people with severe and enduring mental health problems. This particular label has been shown to be associated with less negative reactions relative to other, less politically correct labels and is also considered to be reflective of a condition more likely to change (Penn, & Nowlin-Drummond, 2001). However, an important aspect of this study was the finding that this label did not result in greater behavioral intention on the part of participants to interact with persons with severe mental health difficulties. An additional down side reported by this study was that participants receiving this label as a descriptor, were more likely to attribute responsibility for the condition to the target person, relative to the other labels. Thus it would appear that the idea of a condition likely to change is associated with ideas that the person is responsible for bringing about this change.

Boisvert & Faust (1999), however, reported that the schizophrenia label did not lead members of the public to make significantly more causal attributions for violent behavior to the individual. When members of the public were permitted to

identify environmental stressors preceding violent behaviour, they reduced the extent to which they made attributions about the 'person with schizophrenia' having a history of acting violently. Thus the label of schizophrenia did not distort or bias attributions when participants were provided with a compelling psychosocial context for behaviour. A follow-up study using eighty mental health professionals suggested that practicing clinicians did not perceive the cause of violent behaviour to be more dispositional than situational when the person was given a label of schizophrenia as opposed to no label. Moreover, when clinicians were given information relating to the target individual experiencing increasing environmental stress (psychosocial context) professionals were more likely to rate the person as justified in their behaviour. It would appear that the provision of contextual information relating to psychosis helps to undo some of the well documented effects of labeling.

Symptoms

Another set of signals that may lead to stigma result from the symptoms of severe mental illness, such as inappropriate affect, unusual behaviour, and language. Many of these symptoms are seen as particularly threatening by the public and signals such as these tend to produce more stigmatising reactions than those associated with labels alone (Penn, Kohlmaier, & Corrigan, 2000). Bean, Beiser, Zhang, & Iacono, (1996) found that negative labeling of individuals with a first episode of schizophrenia tends to be related to the length and

intensity of behavioral disturbance prior to hospitalisation. The negative attributions were also associated with older age at onset of psychosis, a long period of deterioration before the onset of psychosis, and poor occupational functioning in the nine months prior to hospitalization. Interestingly, in an experimental study, Penn, Kohlmaier & Corrigan, (2000) found that negative symptoms were more strongly associated with 'conversational social distance' than positive symptoms.

Social skills

Poor social skills that are a function of the disorder may also lead to stigmatising reactions. Deficits in eye contact, body language, severe transgression of the normative rules for social interaction, and choice of discussion topics have the potential for marking a person as mentally ill and consequently can lead to stigma (Meuser, Bellack, Douglas & Wade, 1991). Penn et al, (2000) found that individuals increased their social distance to a person with a diagnosis of schizophrenia in line with the strength of their perceptions about the strangeness of their verbal interactions and social skill.

Physical Appearance

Physical appearance may also act as a cue for stigmatizing attitudes. In particular physical 'unusualness', dress and levels of personal hygiene tend to be

robust predictors of stigma in psychosis (Penn, Meuser & Doonan, 1997). One of the main beliefs held by members of the general public in Nunally's (1961) study was the belief that people suffering from schizophrenia were unkempt and dirty.

Recently, there has been a growing recognition of the impact of general public attitudes towards people with psychological difficulties: indeed stigmatising perceptions seem to be widely held and applied by the general public (UKDoH, 1999b; Wahl, 1999; Crisp et al, 2000). Over the past five decades most of the research on stigma has been conducted in relation to general public attitudes towards mental illness (Nunally, 1961; Hayward & Bright, 1997). This research is primarily descriptive, however it formed the basis for the application and development of social cognitive approaches, such as labeling, stereotypes, and attributions and has much to say about whether society has moved from particular unhelpful attitudes towards people with severe and enduring mental illness diagnoses.

Public Attitudes

There is increasing evidence that stigma and negative attitudes are more prevalent today than at any other time in the recent past. Phelan and colleagues (Phelan, Link, Stueve, & Pescosolido, 2000) found that negative and stereotypic attitudes about people with mental illness actually increased by 2.5 times between the 1950's and the mid 1990's in the U.S. A study which looked at

PAGE

MISSING

IN

ORIGINAL

Some recent work in the UK (Crisp et al, 2000) reported that of 1800 adults interviewed by the Office of National Statistics about 7 types of psychological disorder (depression, panic disorder, dementia, eating disorders, alcohol and drug addiction, and schizophrenia), 80% thought people with a diagnosis of schizophrenia unpredictable and 70% thought them dangerous. Other important responses where there was poor understanding was in terms of public perceptions about response to treatment, likelihood of recovery, ability to 'pull oneself together' and importantly attributions of blame for the causes of the condition. Similar findings were reported by Wahl (1989), in the United States.

Beliefs about causes of psychosis

The kinds of beliefs that people hold about the causes of schizophrenia has been shown to be directly implicated in negative public attitudes. Chou and Mak, (1998) in a two year longitudinal study found that as public confidence in medical model explanations of behaviour associated with a mental illness diagnosis increased, public attitudes towards people so diagnosed, became increasingly negative. Sarbin and Mancuso (1970), and Golding, Becker, Sherman, and Rappaport (1975), found that people agreeing with explanations grounded in a medical model were more likely to reject the person concerned. In an experimental study, Metha and Farina (1997) found that participants in a learning task increased the intensity and duration of electric shocks more quickly if their understanding of their partner's mental health problems was couched in

disease/biological terms than in psychosocial terms. This pattern of findings may have relevance to Estroff's (1989) statement that people can become the thing they are labelled, and may be perceived as fundamentally different from those who do not share the label. Thus holding a biological causal belief can mean that, unlike other conditions where, for example, the individual *has* heart disease or cancer, the person *is* schizophrenic and is something less than 'one of us' (Metha & Farina, 1997; Link & Phelan, 2001). This implies a conceptual separation of 'us' from 'them' and such a separation can be used to justify a range of discriminatory and abusive behaviours towards such an 'out' group (Link & Phelan, 2001; Estroff, 1989). Rothaus, Hanson, Cleveland, & Johnson (1963), found that employers evaluated applicants who explained their problems in terms of disease and nervous breakdown, less favourably than applicants who explained similar problems in terms of relationship difficulties. Read and Harre (2001), found that biological and genetic causal beliefs were related to negative attitudes such as perceptions of being dangerous, antisocial and unpredictable. Similarly, there was a relationship between more people with a mental illness diagnosis known by participants and less negative attitudes. There was also a non-significant trend for a relationship between the number of people with a mental illness diagnosis known by participants and the tendency not to hold biological causal beliefs. This may suggest that knowing people with a psychosis diagnosis reduces the notion of 'outgroup homogeneity' (Ryan & Judd, 1992), provides a psychosocial context for their difficulties and helps to challenge some

of the fixed biological ideas about aetiology, cure or control and potential consequences.

Attitudes of Healthcare Professionals

Research suggests that professionals are not immune to such stigmatizing practices. Indeed many mental health professionals and family physicians report a strong preference for not working with people with severe mental illness diagnoses (Mirabi, Weisman, Magnetti, & Keppler 1985; Lawrie, Martin, McNeill, Drife, Christie, Reid, Wu, Nammary, & Ball, 1998). Cohen and Struening's (1962) study on attitudes of 1200 mental health personnel found three underlying factors that described the attitudes of these professionals towards their patients: those of authoritarianism, benovelence and social restrictiveness. The 'physician' group was the highest in social restrictiveness, while psychologists were found to "occupy the low extremes of benevolence". Wilmouth, Silver & Severy (1987) examined supporters of the NIMBY attitude and found that physicians were the least likely to support a mental health project in their neighbourhood.

Healthcare models of illness

In a study of causal attributions for patients' problems, Barrowclough, Haddock, Lowens, Connor, Pidiswji, & Tracey, (2001), found that staff who held more negative feelings towards patients, also showed a tendency to attribute patient problems to being under the patient's control. Attributions, in this staff group on a low security unit, were predominantly internal and personal. Patients' ratings of

staff feelings towards them showed a strong association with both objective and subjective assessments of staff expressed feelings. Patients therefore were particularly attuned to staff perceptions about them, which has clear implications for 'felt' forms of stigma.

Healthcare professionals subscribing to a more biological perspective have been shown to be less inclined to involve patients in the provision or management of mental health services than are professionals with a psychosocial perspective (Kent & Read, 1998). Fryer and Cohen (1988) studied general hospital staff and found that patients who were labeled 'psychiatric' were rated as less likeable and as having more unfavourable traits and fewer favourable traits than patients labeled 'medical'. Langer and Aberson (1974) asked mental health professionals to assess patients by videotape and found that professionals who subscribed more to a medical illness model of psychosis, rated the patients as more disturbed than did professionals with a social learning perspective. Metha and Farina (1997), suggest three reasons by which the medical model produces such negative reactions. Firstly, viewing distressed people as sick, while discouraging accountability, produces a patronizing parent-child attitude in which they must be treated firmly - "they must be shown how to do things and where they have erred" (social restrictiveness). Hence the harsher treatment. Secondly, believing in 'biochemical aberrations' renders the patient, 'almost another species' (authoritarianism). Thirdly, an illness framework makes us feel vulnerable to being struck down by this condition, whereas psychosocial explanations suggest

their exceptional circumstances will not happen to us (fear and benovelence). This closely corresponds to the patterns of public and professional attitudes uncovered by a number of researchers using multidimensional scaling techniques (e.g., Cohen & Streuning, 1962; Taylor & Dear, 1980; Brockington et al, 1993; Crisp et al, 2000).

Severe mental Illness, social cognition and families

Most attribution research for symptom behaviours in psychosis has been conducted within the concept of expressed emotion (EE) or negative family attitudes. A considerable body of evidence suggests that family environment, particularly those constructs underlying expressed emotion (critical comments, emotional over-involvement and hostility) may exert a significant influence on the course of schizophrenia (Wearden et al, 2000). More specifically poor understanding about schizophrenia in relatives has been proposed as a major source of high levels of expressed emotion (Barrowclough & Tarrier, 1992).

Causal Attributions

The attributions for causes of severe mental illness held by family members have been shown to vary considerably. Since Brewin and colleagues' study a decade ago (Brewin, McCarthy, Duda & Vaughan, 1991), a number of other researchers have supported and clarified their observation that the type of attribution made by relatives was associated with the emotional attitude of the relative towards the patient (e.g., Harrison & Dadds, 1992; Harrison, Dadds, & Smith, 1998,

Weisman, Neuchterlein, Goldstein, & Snyder, 2000). Robinson (1996), found that relative's causal attributions tended to cluster into 3 groups: people based, biology/heredity, and God/chance. Among parents and siblings, poor family functioning was associated with internal attributions (oneself, the patient, or others inside or outside the family) as the cause of the illness. Conversely, no relationship was found between family functioning and more external attributions (genetics, biology, God, or chance). Similarly, Natale & Barron's (1994) study of the mothers of young adults with schizophrenia reported that the most frequently cited causal category was physiological-biological factors; while the most internal was personality of the son. Feelings of guilt were associated with causal explanations characterized as internal. Mechanic, McAlpine, Rosenfield, & Davis, (1994) collected data from a cross-sectional telephone survey of 552 persons with mental illness, most of whom had a current diagnosis of schizophrenia. Participants who attributed their problems to a "physical, medical, or biological" problem in contrast to a "mental illness" reported more positive social relations and higher overall quality of life.

Attributions of Control

Attributions about how much control the patient is perceived to be able to exercise over his or her behaviour has been the subject of much investigation. Overly critical relatives have been shown to have a more internal locus of control, whereas attributions expressed by low-critical relatives were indicative of a more

external locus of control (Hooley, 1998). Consistent with attribution theory, Weisman, Lopez, Karno, & Jenkins (1993) found that families within which there were high levels of critical comments, viewed the illness and associated symptoms as residing within the patient's personal control, more so than did low EE families. Also, family members who perceived the patient as having control over the symptoms of schizophrenia tended to express greater negative emotions such as anger and annoyance toward the patient than did family members who viewed the symptoms as beyond the patient's personal control. Symptoms reflecting behavioral deficits such as poor hygiene were criticized more often than symptoms reflecting behavioral excesses, such as hallucinations (Weisman, Nuechterlein, Goldstein & Snyder 1998 Weisman & Lopez, 1997).

Looking at attributional differences within the EE construct, Barrowclough Johnston, & Tarrier, (1994), reported that, within the high EE group, relatives with marked emotional overinvolvement were similar to the low EE group, with problems attributed to factors more external to and uncontrollable by the patient. Relatives with high criticism gave more causes internal to the patient and hostile relatives also tended to perceive the causes to be controllable by, and personal to, the individual with schizophrenia. Attribution variables were also better predictors of patient relapse at 9 month follow-up than were EE measures. Similarly, Lopez, Nelson, Snyder & Mintz (1999) reported that internal attributions of control in low over-involved families were related to family members' warmth and criticism and to patients' clinical outcomes.

Lay theories and the common-sense model of psychosis.

Some researchers posit that it is not a necessary condition that someone in the immediate context of the person needs to have engaged in obvious forms of discrimination for the individual to feel stigmatised (eg., Link, 1987; Wahl, 1989). The discrimination lies behind the immediate situation and rests instead on the formation and sustenance of stereotypes and lay theories or common sense models of illness. People develop conceptualisations of mental illness early in life as part of acculturation (Angermeyer & Matschinger, 1996; Scheff, 1966, Wahl, 1995). Once in place, people's conceptions become a lay theory, or common sense model of what it means to have a mental illness (Angermeyer & Matchinger, 1994; Furnham & Bower, 1992). Research on lay theories has demonstrated that people who begin the task of social perception with different starting assumptions, follow divergent cognitive paths and reach different social endpoints (Levy, Plaks, Hong, Chiu, & Dweck, 2001). Perceptions and expectations on the part of the patient, their family and members of the public are formed as to whether most people will reject an individual with mental illness as a friend or partner, an employee or a neighbour and whether most people will devalue a person with psychosis: deeming them to be less trustworthy, intelligent and competent (Link et al, 1997). For the person who develops a psychotic illness, these cognitions become personally relevant because of the very real possibility of discrimination and devaluation. If one believes that others will devalue and reject people with mental illness, one must now fear that this rejection applies personally. Moreover 'felt' stigma beliefs would be expected to

be associated not only with causal or control attributions but with a more substantive implicit or common-sense model of psychosis.

Common-sense models about a disorder tend to be based on generic memorised information about wellness and disorder, information received in the medical domain, and lay information from family and friends and from the wider media (Wahl, 1999). Lay models have received increased attention in recent years as evidence supporting the importance of interpretative processes between objective demands and subjective states has entered the literature as part of a general information processing approach to cognition and behaviour (Corrigan & Watson, 2002). Research in physical illness has demonstrated that models of illness are based around a number of components – identity, cause, time-line, consequences, control, coherence, and emotional representations, and one study on the relatives of patients with psychosis (Barowclough, Lobban, Hatton & Quinn, 2001) has shown that this model is also a reliable measure of carer's perceptions of schizophrenia. However, the effects of such models and the relations between the individual components and stigma, or the relation between the respective models of the patient and carer and patient perceptions of stigma has not been examined in psychosis to date.

Stigma and Families

The stigma of mental illness can also attach itself to relatives. This 'associative' (Mehta & Farina, 1988) or 'courtesy' (Goffman, 1963) stigma has received relatively little attention from researchers, in spite of its probable association with family burden (Creer, 1975; Martens & Addington, 2001; Phelan, Bromet, & Link, 1998).

The available evidence suggests that higher family socioeconomic status (SES) is associated with greater perceptions of stigma and more extreme reactions to stigma by relatives (Angermeyer, et al, 1987; Phelan et al, 1998). This finding tends to be interpreted in line with higher SES families having more in the way of status or reputation to lose.

Yarrow, Clausen & Robbins (1965) found that carers use strategies of concealment and withdrawal, which tend to mirror the strategies used by patients experiencing stigma (Link et al, 1991), whilst Kreisman & Joy (1974) reported family members attempting to cope with underlying feelings of shame and guilt. Hatfield (1978) observed that marital disruption, blame, grief and helplessness were common results of caring for a relative with schizophrenia. Phelan et al, (1998) reported that about half the parents and spouses of recently hospitalised patients reported some degree of concealment about their hospitalisation. In addition, concealment was higher among relatives of female patients, relatives of patients with less severe positive symptoms, and among relatives who lived apart

from the patient. In a recent study on family burden in schizophrenia, Martens & Addington (2001) reported that the stigma subscale from the experience of caregiving inventory showed the highest correlation with relatives' psychological wellbeing, (over and above assessments of dependency, problems with family, difficult behaviours and feelings of loss). In a study of families in the UK, in which a family member was diagnosed with schizophrenia and was living at home, 50% of family members reported severe impairment of their own health as a consequence of their relative's condition (Creer, 1975).

Coping with stigma

Coping strategies in response to stigma in people diagnosed with severe mental illness have not been the subject of much research to date. In general, the small number of research studies has found three mainstays of coping with stigmatising conditions (Link et al 1989). These coping strategies are *secrecy* - where people decide to conceal their treatment history from employers, relatives or intimate partners to avoid rejection (Goffman, 1963; Jones et al, 1984); *selective avoidance or withdrawal* - where people limit social interaction to those who know about and tend to accept one's stigmatised condition; and *preventive telling* - in the hope of enlightening others so as to ward off negative attitudes (Link Mirotznik and Cullen, 1991). This finding has some ecological validity as mental health professionals have been shown to recommend these coping orientations for their patients more frequently than not (Angermeyer, Link & Majcher-Angermeyer, 1987). Link et al, (1991) reported that the three coping

strategies show consistent effects in the direction of producing more harm than good, being associated with unemployment and demoralization. Interestingly Wahl & Harman (1989), reported that while 56% of their sample identified stigma as having a large impact on the lives of family members, only 8-22% identified specific ways that stigma had affected them personally. These findings suggest that the expectation of stigma may be greater than the actual experience of it. Personal reactions to severe mental illness stigma may result in significant loss of self-esteem in some people, others may be energised or empowered by prejudice and express righteous anger, while others still, neither appear to lose self-esteem nor become angry at stigma, and are instead able to ignore the effects of public prejudice altogether (Harp, 1994). Corrigan and Watson (2002) have developed a situational model of the personal response to mental illness stigma based on the collective representations that are primed in a particular situation, the individual's perception of the legitimacy of stigma in the situation, and the individual's identification with the larger group of people with mental illness.

Patients who accept the diagnosis of mental illness may feel internal pressure to conform to a stereotype of incapacity and worthlessness, adopting a disabled role and becoming more dependent. As a result, insight may be rewarded with poor outcome (Warner, 1984). Doherty (1975) found that hospitalised inpatients who accepted they were mentally ill were rated as showing the least improvement and those who denied that they were mentally ill did better.

Similarly, Warner (1989) reported that patients who accepted they were mentally ill had lower self-esteem and a perception of poorer control over their lives. Those who found mental illness most stigmatizing had the worst self esteem and the weakest sense of mastery. According to Warner (1999), "stigma creates a catch 22 for people with schizophrenia – accepting the illness can mean losing the capacity to cope with it" (p29).

Individual's who have entered the healthcare system for treatment of their psychosis, may act less confidently, more defensively, or they may simply avoid any contact that may be deemed threatening in this respect. The result may appear to be unrewarding interactions with potential stigmatizers (Farina, Allen & Saul, 1968), low self esteem (Wright, Gonfrien & Owens, 2000), psychological distress (Link et al, 1997), unemployment and loss of income (Link, 1987), constriction in social networks (Link et al, 1989), and diminution of patients quality of life (Rosenfeld, 1997)

Given what has been learned from research into the consequences and mechanisms of stigma, how might we intervene to challenge and change the stigma of severe and enduring mental illness?

Intervening with stigma and discrimination

A relatively large number of investigations have examined ways to change mental health stigma and discrimination. While some clinicians have suggested as many as 6 routes to destigmatisation (e.g., Haghighat, 2000), these have tended to revolve around three main areas: protest, education and contact. User groups protest inaccurate and hostile representations of mental illness as a way to challenge the stigma they represent. They tend to offer the message to the media – stop reporting inaccurate representations of mental illness: and to the public - stop believing negative views about mental illness.

Media Protest

Wahl (1995) reports the mass media to be the most common source of general public's knowledge about mental illness. Television is viewed about 4 to 6 hours per day in western societies (Cuenca, 2001), and the nature of what is offered in terms of programming is pretty much similar, certainly in the US (Gerbner, Gross, Morgan, & Signorelli, 1980). Viewers are not critically appraising the images and information they are receiving in the same way that they might with news reports. The result is that inaccurate and unhelpful stereotypes have great power to influence public notions of severe mental illness (Wahl, 1995). Whilst there is good reason for mental health professionals to blame the media for the promulgation of the 'violent madman' stereotype (Allen & Nairn, 1997; Wahl, 1992), the attitudes of such professionals have been shown to be not dissimilar to those of the journalists they castigate (Day & Page, 1986; Monahan, 1992).

There is a paucity of empirical research on the impact of protest campaigns. There is some evidence that protest and suppression may in fact lead to a rebound effect such that when people are ordered to suppress negative stereotypes, they tend to become more sensitized to them and this may lead to an increase in recollections about the stigmatised group (Macrae et al, 1996).

In addition, protest tends to be a reactive strategy, which has typically been used to suppress behaviour rather than attitudes and attributions and may only be effective for those people who already hold positive ideas about people with severe mental illness. In a study on who is likely to participate in campaigns against mental illness stigma, Corrigan, River, Lundin, Wasowski, Campion, Mathisen, Goldstein, Gagnon, Bergman, & Kubiak, (1999) found that people who signed a petition against inaccurate media representations of mental illness were less likely to believe persons with mental illness were to blame for their disorder or should be avoided. Thus, attributions about controllability and responsibility were associated with anti-stigma behaviour. This suggests that an additional education component about psychosis is a requirement for anti-stigma campaigns.

Public Education

The effectiveness of education as a means of reducing stigma has some empirical support in that people who show a better understanding of mental illness are less likely to endorse stigma and discrimination (Link & Cullen, 1985; Brockington et al, 1993). Similarly participation in education programmes has been shown to reduce negative attitudes about people with severe mental illness, and such programmes have been shown to be effective for range of people from members of the general public (Holmes et al, 1999; Penn et al, 1999) to medical and nursing students (Keane, 1990; 1991). However, there is very little empirical research on what the active ingredients of public psycho-education programmes should be.

According to Read and Harre (2001), "There is now sufficient evidence to abandon the 'mental illness is an illness like any other' approach to improving attitudes" The 'mental illness is an illness like any other' notion often advanced as the gold standard of pubic attitude change has been shown to be less helpful than we might like to believe. Whilst this approach was an attempt to replace the moral depravity model with a medical model (bad to mad), the hope that the protective properties of the sick role would help to remove attributions of blame, responsibility and accountability tends not to be supported by research (Metha & Farina, 1997; Read & Harre, 2001).

Read & Harre (2001) recommend presenting people and their difficulties in the context of their life events rather than portraying them as symptoms of biologically based illnesses. Such holistic psychosocial approaches have some indirect empirical support which has been reviewed previously showing the harmful and stigma-inducing effects of beliefs in biologically based causal attributions (e.g., Boisvert & Faust 1999; Chou & Mak, 1998).

Promoting Contact and Social Inclusion

One of the most consistent findings that has emerged from the research on stigma and a finding that has often emerged as a sub-hypothesis relative to a more substantive question has been the finding that negative public attitudes tend to be less pronounced in people who have had personal contact with individuals with psychosis. This relationship seems to be both robust and monotonic, such that the more people with a severe mental illness diagnosis known by members of the general public the less likely these members of the public are to hold negative attitudes towards people so diagnosed (e.g., Morrison et al, 1993; Penn et al, 2000). Contact has been perceived to be a strategy that is less likely to promote a thought-suppression rebound effect (Johnston & Macrae, 1994), permitting individuals to challenge and change their attitudes in the light of real-world evidence.

Corrigan and colleagues (Corrigan, River, Lundin, Penn, Uphoff, Campion, Mathisen, Gagnon, Bergman, Goldstein, & Kubiak, 2001), investigated the effects of education, contact and protest on attributions about schizophrenia. Education comprised a review of seven myths (e.g., myths about violence, dangerousness, homelessness and so on) and presentation of research findings that disputed such myths. Protest comprised discussion around the disrespectful ways in which persons with mental illness were portrayed in the media; and contact involved participants listening to a 10 minute presentation by one of two persons who discussed their history of severe mental illness. Results demonstrated that education led to improved attributions about psychosis, while contact produced positive changes that exceeded education. Protest yielded no significant changes in attributions. Views about controllability seemed less amenable to education. This finding is unfortunate as such attributions tend to be strongly related to family attitudes and societal rejection (Hooley & Licht, 1997).

Some recent research has begun to examine the effects of specific stigmatizing attitudes towards people with mental illness diagnoses. Corrigan, Backs-Edwards, Green, Lickey-Diwan & Penn (2001) examined the paths between behavioural discrimination and two prejudicial attitudes which have previously been found to be widely endorsed by both the general public as well as healthcare professionals - those of benevolence and authoritarianism. Using path analytic procedures, the statistical relation between benevolence and social distance was stronger than the path between authoritarianism and social

distance. This finding may be reflective of attributions of irresponsibility arising from beliefs that people with mental illness diagnoses are child-like. In addition individuals who were more familiar with mental illness and people from ethnic minorities were less likely to support prejudicial attitudes.

DISCUSSION

This review has examined the current psychological understanding of stigma as it relates to severe mental illness. The concept of stigma is defined both by the individual and the society or culture in which the individual is located. The literature reviewed spans half a century and in this time some understanding has been obtained about the effects of stigma and the mechanisms by which stigma comes into being and is maintained. It has also begun to provide some limited answers to the question of what can be done to challenge and change stigma and discrimination. However, inconsistencies in definition, a tendency to conduct descriptive research and lack of persistent empirical interest in this field have contributed to the slow pace of research and has meant that the integration of the products of this research into evidence-based interventions has been poor. This slow pace of forward momentum is itself probably an outcome of the pervasiveness of stigma, in so far as comprehensive research programmes into the stigma of severe mental illness have traditionally been unlikely to attract 'hard' research funding (UKDoH, 2001). Despite this, research over the last decade has attempted to formulate research questions around a more

compelling and substantive theoretical base. This review has addressed the question of whether there is sufficient evidence that stigma is a serious, pervasive and damaging element for people with severe mental illness, it has examined what is currently known about the mechanisms that drive stigma and discrimination, and has provided an examination of the factors that might bring about lasting change in stigma.

Future Research

One of the main criticisms of research on stigma has been that such research has a focus on the individual. Whilst Goffman did not maintain an investment in the differences between types of stigma, the unifying theory of spoilt identity and its management according to some commentators, "loaded his analysis towards a highly individualistic rendering of the subject – the individual appears in his analysis as the sole bearer of value" (Das, 2001). Goffman called for "a language of relationships not attributes" (1963, p.3), and recognised that stigma is a consequence of individual and societal cognitions. Subsequent research and practice has often transformed stigmas or marks into attributes of persons (Fine & Asch, 1988). The stigma or mark is attributed to something in the person rather than a designation or tag that others affix to the person. In contrast to stigma, discrimination focuses the attention on to the producers of exclusion and rejection - those who do the discriminating rather than to the people who are the recipients of these behaviours (Sayce, 1998). According to Oliver (1992),

research examining the sources and consequences of pervasive socially shaped exclusion from social and economic life are far less common. There is a clear need to examine the factors that might permit members of the public to remove themselves from such socially sanctioned actions. Similarly there is a need to examine in what ways enacted stigma may be discrepant with felt stigma. Ultimately the belief that one is stigmatised is of course subjective and may not necessarily be concordant with the objective reality of day to day events. It is clear that some individuals who have a diagnosis of severe mental illness do not experience their condition as a source of stigma, although they may recognise that it retains the potential to be so (Corrigan & Watson, 2002). Research has yet to examine the psychological factors and processes that might account for this individual variation in felt stigma and many questions remain to be addressed. In particular what are the factors that 'buffer' the effects of discrimination and stigma on the individual's perception of themselves as a member of a stigmatised group.

This review has also demonstrated the manner in which cognitive factors such as attitudes and beliefs become integrated into a stereotype, which in turn appears to mediate the effects of these other factors on ideas about the phenomenology of the disorder and also direct the selection of particular behaviours towards the patient. Attributional processes lie at the heart of social cognition perspectives on severe mental illness, and are a key feature of how individuals, family members and members of the general public attempt to make sense of the complex array of features and signals of the individual with psychosis. In

particular attributions play a critical role in how significant others attempt to assimilate and accommodate such information into their own view of the patient and their disorder.

An examination of the implicit models (for example, ideas about causes, consequences, symptoms, recurrence, control, cure and so on) held by people with psychosis as well as their family members and the public is only beginning to be addressed. One recent study (Barrowclough et al, 2001) examined the model held by relatives of patients with psychosis, however patients and general public perceptions have not been examined in detail, despite the role that such models may have in promoting stigma (Angermeyer & Matchinger, 1997). Moreover, substantive research needs to be conducted examining the potential for mismatch between implicit models held by respective parties and the effects of discrepant patient-relative-general public models and their impact on distress, coping and stigma.

Of overwhelming significance is the question of how empirical research might inform interventions for tackling stigma. The basic research is only now beginning to provide some limited answers to this question in so far as we can state that contact seems to be the most effective strategy in changing attributions about people with mental illness diagnoses. However, we cannot state that changes in attitudes or attributions readily translate into changes in behaviour. Similarly we do not yet know what the specific and effective ingredients of anti-stigma

interventions are. It is important to state that while the issue of stigma is moving towards becoming a collectively defined social problem and acquiring social legitimacy, this has been almost exclusively driven by mental health consumer groups. Clinicians may assist this process by incorporating the issue of stigma and discrimination into academic and public debate and being open to the likelihood that we too are adept at stigmatising and discrimination. If we are unwillling to adopt this role, we will miss out on an opportunity for open and honest therapeutic collaboration.

References

Allen, R. & Nairn, R.G. (1997). Media depictions of mental illness: An analysis of the use of dangerousness. *Australian and New Zealand Journal of Psychiatry,* **31:** 375-381.

Alvidrez, J. (1999). Ethnic variations in mental health attitudes and service use among low-income African American, Latina, and European American young women. *Community Mental Health Journal.* **35**: 515-530.

Angermeyer, M.C. & Matschinger, H. (1995). Violent attacks on public figures by persons suffering from psychiatric disorders: Their effect on the social distance towards the mentally ill. *European Archives of Psychiatry and Clinical Neuroscience,* **245**: 159-164

Angermeyer, M.C & Matschinger, H. (1996). Relative's beliefs about the causes of schizophrenia. *Acta Psychiatrica Scandinavica*, **93:** 199-204.

Angermeyer, M.C., Link, B.G. & Majcher-Angermeyer, A. (1987). Stigma perceived by patients attending modern treatment settings. *Journal of Nervous and Mental Disease,* **175:** 4-11.

Baronet, A. (1999). Factors associated with caregiver burden in mental illness: a critical review of the research literature. *Clinical Psychology Review,* **19:** 819 – 841.

Barker, S., Lavender, T., & Morant, N. (2001). Client and family narratives on schizophrenia. *Journal of Mental Health,* **10**: 199-212

Barrowclough C. & Tarrier, N. (1992). *Families of Schizophrenic Patients: Cognitive-Behavioural Intervention.* London. Chapman and Hall.

Barrowclough, C., Lobban, F., Hatton, C. & Quinn, J. (2001). An investigation of models of illness in carers of schizophrenia patients using the Illness Perception Questionnaire. *British Journal of Clinical Psychology,* **40:** 371-385.

Barrowclough, C., Haddock, G., Lowens, I., Connor, A., Pidiswji, J., & Tracey, N. (2001). Staff expressed emotion and causal attributions for client problems on a low security unit: an exploratory study. *Schizophrenia Bulletin,* **27:** 517-526.

Barrowclough, C., Johnston, M. & Tarrier, N. (1994). Attributions, expressed emotion, and patient relapse. An attributional model of relatives response to schizophrenic illness. *Behaviour Therapy,* **25:** 67-88.

Bean, G., Beiser, M., Zhang, W.W. & Iacono, W. (1996). Negative labelling of individuals with first episode schizophrenia: the effect of premorbid functioning. *Schizophrenia Research*, **22**(2):111-118.

Bordieri, J. & Drehmer, D. (1986). Hiring decisions for disabled workers: Looking at the cause. *Journal of Applied Social Psychology,* **16:** 197-208.

Boisvert, C.M. & Faust, D. (1999). Effects of the label 'schizophrenia' on causal attributions of violence. *Schizophrenia Bulletin,* **25:** 479-491.

Brewin, C.R., McCarthy, B., Duda, K. & Vaughan, C.E. (1991). Attribution and expressed emotion in the relatives of patients with schizophrenia. *Journal of Abnormal Psychology,* **100:** 546-554.

Brockington, I., Hall, P., Levings, J. & Murphy, C. (1993). The community's tolerance of the mentally ill. *British Journal of Psychiatry,* **162:** 93-99.

Butzlaff, R.L. & Hooley, J.M. (1998). Expressed emotion and psychiatric relapse: A meta analysis. *Archives of General Psychiatry,* **55:** 547-552.

Byrne, P. (1997). Psychiatric stigma: past, passing and to come. *Journal of the Royal Society of Medicine,* **90:** 618-621.

Chamberlin, J. (1997) A working definition of empowerment. *Psychiatric Rehabilitation Journal*, **20:** 43-46.

Chou, K. & Mak, K. (1998). Attitudes to mental patients among Hong Kong Chinese: A trend study over two years. *International Journal of Social Psychiatry,* **44:** 215-224.

Cohen, J. & Streuning, E.L. (1962). Opinions about mental illness in the personnel of two large mental hospitals. *Journal of Abnormal and Social Psychology,* **64:** 349-360.

Corrigan, P.W. (2000). Mental health stigma as social attribution: Implications for research methods and attitude change. *Clinical Psychology: Science and Practice,* **7:** 48-67.

Corrigan, P.W., Backs-Edwards, A., Green, A., Diwan, S.L., Penn, D.L. (2001). Prejudice, social distance, and familiarity with mental illness. *Schizophrenia Bulletin,* **27:** 219-225.

Corrigan, P.W., River, L.P., Lundin, R.K., Penn, D.L., Uphoff-Wasowski, K., Campion, J,, Mathisen, J., Gagnon, C., Bergman, M., Goldstein, H., Kubiak, M.A., (2001). Three strategies for changing attributions about severe mental illness. *Schizophrenia Bulletin,* **27:** 187-195.

Corrigan, P.W., River, L.P., Lundin, R.K., Uphoff-Wasowski, K., Campion, J,, Mathisen, J., Goldstein, H., Gagnon, C., Bergman, M., Kubiak, M.A. (1999). Predictors of participation in campaigns against mental illness stigma. *Journal of Nervous and Mental Disease,* **187:** 378-380.

Corrigan, P.W. Green, A., Lundin, R., Kubiak, M.A. & Penn, D.L. (2001). Familiarity with and social distance from people who have serious mental illness. *Psychiatric Services,* **52**: 953-958.

Corrigan, P.W. & Watson, A.C. (2002). The paradox of self-stigma and mental illness. *Clinical Psychology: Science and Practice,* **9:** 35-53.

Creer, C. (1975). Living with schizophrenia. *Social Work Today,* **6:** 2-7.

Crisp, A.H., Gelder, M.G., Rix, S., Meltzer, H.I. & Rowlands, O. (2000). Stigmatisation of people with mental illness. *British Journal of Psychiatry,* **177:** 4-7.

Crisp, A.H. (2000). Changing minds: Every family in the land: An update on the College's campaign. *Psychiatric Bulletin,* **24**: 267-268

Crocker, J., Major, B. & Steele, C.(1998). Social stigma. In D.T. Gilbert, & S.T. Fiske, (Eds). *The Handbook of Social Psychology.* Vol. 2 (4th ed.). (pp. 504-553). New York: McGraw-Hill.

Cuenca, O. (2001). Mass media and psychiatry: an introduction. *Current Opinion in Psychiatry,* **14:** 527-528.

Cuipers, P. & Stam, H. (2000). Burnout among relatives of psychiatric patients attending psychoeducational support groups. *Psychiatric Services,* **51;** 375-379.

Cumming, E. & Cumming, J. (1957). *Closed Ranks: An Experiment in Mental Health.* Cambridge. Massachusetts. Harvard University Press.

D'Arcy, C. & Brockman, J. (1976). Changing public recognition of psychiatric symptoms? Blackfoor revisited. *Journal of Health and Social Behaviour,* **17:** 302-310.

Davies, T.W. & Morris, A. (1989). A comparative quantification of stigma. *Social Work and Social Sciences Review,* **1**(2): 109-122.

Day, D.M. & Page, S. (1986). Portrayals of mental illness in Canadian newspapers. *Canadian Journal of Psychiatry,* **31:** 813-817.

Das, V. (2001). Stigma, contagion, defect: Issues in the anthropology of public health. Presented at: Stigma and Global Health: Developing a Research Agenda. an International Conference. *September 5-7, 2001. Bethesda, Maryland.* On-line at http://www.stigmaconference.nih.gov.

Doherty, E.G. (1975). Labeling effects in psychiatric hospitalization: A study of diverging patterns of inpatient self-labeling processes. *Archives of General Psychiatry,* **32:** 562-568.

Druss B.G., Bradford, W.D., Rosenheck, R.A., Radford, M.J., Krumholz, H.M. (2000). Mental disorders and use of cardiovascular procedures after myocardial infarction. *Journal of the American Medical Association,* **283**: 506-511.

Druss B.G., Bradford, W.D., Rosenheck, R.A., Radford, M.J., Krumholz, H.M. (2001). Quality of medical care and excess mortality in older patients with mental disorders. *Archives of General Psychiatry*, **58**:565-72.

Eckman, T.A., Wirshing, W.C., Marder, S.R., Liberman, R.P. Johnston-Cronk, K., Zimmermann, K. & Mintz, J. (1992). Technique for training schizophrenic patients in illness self-management: A controlled trial. *American Journal of Psychiatry,* **149:** 1549-1555.

Estroff, S.E. (1989). Self, identity and subjective experiences of schizophrenia: in search of the subject. *Schizophrenia Bulletin*, **15:**189-196.

Fryer, J.H. & Cohen, L. (1988). Effects of labeling patients 'psychiatric' or 'medical': favourability of traits ascribed by hospital staff. *Psychological Reports,* **62:** 779-793.

Farina, A., Allen, J.G. & Saul, B.B. (1968). The role of the stigmatized person in affecting social relationships. *Journal of Personality,* **36:**169-82.

Farina, A. & Felner, R.D. (1973). Employment interviewer reactions to former mental patients. *Journal of Abnormal Psychology,* **82:** 268-272.

Fine, M. & Asch, A. (1988). Disability beyond stigma: social interaction, discrimination, and activism. *Journal of Social Issues,* **44**:3-22.

Furnham, A. & Bower, P. (1992). A comparison of academic and lay theories of schizophrenia. *British Journal of Psychiatry,* **161:** 201-210.

Fycock, J. & Stangor, C. (1994). The role of memory biases in stereotype maintenance. *British Journal of Social Psychology,* **33:** 331-344.

Gerbner, G., Gross, L., Morgan, M. & Signorelli, N. (1980). The 'mainstreaming' of America: Violence profile No. 11. *Journal of Communication,* **30:** 10-29.

Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity.* Englewood cliffs, N.J. Prentice Hall.

Golding, S.L. Becker, E., Sherman, S. & Rappaport, J. (1975). The Behavioural Expectations Scale: Assessment of expectations for interaction with the mentally ill. *Journal of Consulting and Clinical Psychology,* **43:** 109.

Greenley, J. (1986). Social control and expressed emotion. *Journal of Nervous and Mental Diseases,* **174:** 24-30.

Haghighat, R. (2001). A unitary theory of stigmatisation: Pursuit of self-interest and routes to destigmatisation. *British Journal of Psychiatry,* **178:** 207-215

Hall, P., Brockington, I.F., Levings, J. & Murphy, C. (1993). A comparison of responses to the mentally ill in two communities. *British Journal of Psychiatry,* **162:** 99-108.

Hamilton D.L & Rose, R.L (1980). Illusory correlation and the maintenance of stereotypic beliefs. *Journal of Personality and Social Psychology,* **39:** 832-845.

Harp, H.T. (1994). Empowerment of mental health consumers in vocational rehabilitation. *Psychosocial Rehabilitation Journal,* **17:** 83-89.

Harrison CA, & Dadds MR. (1992). Attributions of symptomatology: an exploration of family factors associated with expressed emotion. *Australian and New Zealand Journal of Psychiatry* 26(3):408-16

Harrison, C.A., Dadds, M.R. & Smith, G. (1998). Family caregivers' criticism of patients with schizophrenia. *Psychiatric Services,* **49:** 918-924.

Hatfield, A. (1978). Psychosocial costs of schizophrenia to the family. *Social Work,* **23:** 355-359.

Hayward, P. & Bright, J.A. (1997). Stigma and mental illness: A review and critique. *Journal of Mental Health*, **6**: 345-354.

Holmes, P., Corrigan, P.W., Williams, P., Canar, J. & Kubiak, M. (1999). Changing public attitudes about schizophrenia. *Schizophrenia Bulletin,* **25:** 447-456.

Holmes, P.E. & River, L.P. (1998). Individual strategies for coping with the stigma of severe mental illness. *Cognitive and Behavioral Practice,* **5**: 231-239

Hooley, J.M. (1998). Expressed emotion and locus of control. *The Journal of Nervous and Mental Disease,* **186:** 374-378.

Huxley, P. (1993a). Location and stigma: A survey of community attitudes to mental illness: II. Community mental health facilities--anonymity or invisibility. *Journal of Mental Health*, **2**: 157-164

Huxley, P. (1993b). Location and stigma: A survey of community attitudes to mental illness: 1. Enlightenment and stigma. *Journal of Mental Health*, **2**: 73-80

Johnston, L.C. & Macrae, C.N. (1994). Changing social stereotypes: the case of the information seeker. *Journal of Social Psychology,* **24:** 581-592.

Jones, E., Farina, A., Hastorf, A., Markus, H., Miller, D.T. & Scott, R. (1984). *Social Stigma: The Psychology of Marked Relationships.* New York. Freeman.

Kahneman, D., Slovic, P. & Tverskey, A. (1982). *Judgement Under Uncertainty: Heuristics and Biases.* Cambridge. Cambridge University Press.

Kay, S.R (1991) *Positive and Negative Syndromes in Schizophrenia: Assessment and Research.* New York. Brunner Mazel.

Keane, M. (1990). Contemporary beliefs about mental illness among medical students: implications for education and practice. *Academic Psychiatry,* **14:** 172-177.

Keane, M. (1991). Acceptance versus rejection: Nursing students' attitudes about mental illness. *Perspectives in Psychiatric Care,* **27:** 13-18.

Kent, H. & Read, J. (1998). Measuring consumer participation in mental health services: Are attitudes related to professional orientation. *Journal of Social Psychiatry,* **44:** 295-310.

Kreisman, D.E. & Joy, V.D. (1974). Family response to the illness of a relative: A review of the literature. *Schizophrenia Bulletin,* **10:** 34-57.

Lamy, R.E. (1966). Social consequences of mental illness. *Journal of Consulting and Clinical Psychology,* **30:** 450-455.

Langer, E.J. & Abelson, R.P. (1974). A patient by any other name: Clinician group difference in labeling bias. *Journal of Consulting and Clinical Psychology,* **42:** 4-9.

Lawrie, S.M., Martin, K., McNeill, G., Drife, G., Christie, P., Reid, A., Wu, P., Nammary, S. & Ball, J. (1998). General practitioners' attitudes to psychiatric and medical illness. *Psychological Medicine,* **28:** 1463-1467.

Levy, S.R., Plaks, J.E., Hong, Y.y., Chiu, C.y. & Dweck, C.S. (2001). Static versus dynamic theories and the perception of groups: Different routes to different destinations. *Personality and Social Psychology Review,* **5:** 156-168.

Link, B.G. (1982). Mental patient status, work and income: An examination of the effects of a psychiatric label. *American Sociological Review,* **47:** 202-215.

Link, B.G. (1987). Understanding labeling effects in the area of mental disorders: An assessment of the effects of expectations of rejection. *American Sociological Review,* **52:** 96-112.

Link, B.G. & Cullen, F.T. (1986). Contact with the mentally ill and perceptions of how dangerous they are. *Journal of Health and Social Behaviour,* **27:** 289-303.

Link, B.G., Struening, E.L. Rahav, M.& Phelan, J.C. (1997). On stigma and its consequences: Evidence from a longitudinal study of men with dual diagnoses of mental illness and substance abuse. *Journal of Health and Social Behavior,* **38:** 177-190.

Link, B.G, Mirotznik, J. & Cullen, F.T (1991). The effectiveness of stigma coping orientations: Can negative consequences of mental illness labeling be avoided. *Journal of Health and Social Behaviour,* **32:** 302-320.

Link, B.G., Cullen, F.T., Struening, E.L., Shrout, P.E. & Dohrenwend, B.P. (1989). A modified labeling theiry approach to mental disorders: An empirical assessment. *American Sociological Review,* **54:** 400-423.

Link, B.G. & Phelan, J.C (2001). On stigma and its public health implications. Presented at Stigma and Global Health: Developing a Research Agenda. an International Conference. *September 5-7, 2001. Bethesda, Maryland.* On-line at http://www.stigmaconference.nih.gov.

Lopez SR, Nelson KA, Snyder KS, Mintz J. (1999). Attributions and affective reactions of family members and course of schizophrenia. *Journal of Abnormal Psychology.* 108(2):307-14

Lyons, M. & Ziviani, J. (1995). Stereotypes, stigma, and mental illness: Learning from fieldwork experiences. *American Journal of Occupational Therapy,* **49**: 1002-1008

Lyons, D., El Sayed, O.A., & Matthew, V.M. (2001). New unit on old ground or general hospital – where do patients want inpatient treatment. *Irish Journal of Psychological Medicine,* **18:** 129-131.

Macrae, C.N. & Bodenhausen, G.V. (2001). Social cognition: Categorical person perception. *British Journal of Psychology,* **92:** 239-255.

Macrae, C.N., Milne, A.B. & Bodenhausen, G.V. (1994). Stereotypes as energy saving devices: A peek inside the cognitive toolbox. *Journal of Personality and Social Psychology,* **66:** 37-47.

Martens, L. & Addington, J. (2001). The psychological well-being of family members of individuals with schizophrenia. *Social Psychiatry and Psychiatric Epidemiology,* **36:** 128-133.

McGorry, P.D., Phillips, L.J. & Yung, A.R. (2001). Recognition and treatment of the pre-psychotic phase of psychotic disorders: frontier or fantasy? In T. McGlashan, S.A. Mednick. P., Libiger, J. & J.O Johanssen (Eds.) *Early Intervention in Psychiatric Disorders.* Kluwer. The Netherlands.

Mehta, S. & Farina, A. (1997). Is being "sick" really better? Effect of the disease view of mental disorder on stigma. *Journal of Social and Clinical Psychology*, **16**: 405-419

Metha, S. & Farina, A. (1988). Associative stigma: Perceptions of the difficulties of college-aged children of stigmatized fathers. *Journal of Social and Clinical Psychology,* **7:** 192-202.

Mechanic, D., McAlpine, D., Rosenfield, S. Davis, D. (1994). Effects of illness attribution and depression on the quality of life among persons with serious mental illness. *Social Science and Medicine*, **39**: 155-164

Meuser, K.T., Bellack, A.S., Douglas, M.S. & Wade, J.H. (1991). Prrediction of social skill acquisition in schizophrenic and major affective disorder patients from memory and symptomatology. *Psychiatry Research,* **37:** 281-296.

Mirabi, M., Weisman, M.L., Magnetti, S.M. & Keppler, K.N. (1985). Professional attitudes towards the chronic mentally ill. *Hospital and Community Psychiatry,* **36:** 404-405.

Monahan, J. (1992). Mental disorder and violent behaviour: Perceptions and evidence. *American Psychologist,* **47:** 511-521.

Morone, J.A. (1997). Enemies of the people: The moral dimension to public health. *Journal of Health Politics, Policy and Law,* **22:** 993-1020.

Morrison, M., de Man, A.F. & Drumheller, A. (1993). Correlates of socially restrictive and authoritarian attitudes towards mental patients in university students. *Social Behaviour and Personality,* **21:** 333-338.

Natale, A. & Barron, C. (1994). Mothers' causal explanations for their son's schizophrenia: relationship to depression and guilt. *Archives of Psychiatric Nursing*, **8:** 228-36.

Nisbet, R.E. & Kunda, Z. (1985). Perception of social distributions. *Journal of Personality and Social Psychology*, **48:** 297-311.

Nunally, J.C. (1961). *Popular Conceptions of Mental Health: Their Development and Change.* New York: Holt, Rinehart and Winston.

Office of National Statistics (1998). *Labour Force Survey (1997/8).* London. Office of National Statistics.

Okazaki, S. (2000). Treatment delay among Asian-American patients with severe mental illness. *American Journal of Orthopsychiatry*, **70**: 58-64

Oliver M. (1992). *The Politics of Disablement.* Basingstoke: MacMillan.

Penn, D.L. & Nowlin-Drummond, A. (2001). Politically correct labels and schizophrenia: A rose by any other name? *Schizophrenia Bulletin,* **27:** 197-203

Penn, D.L., Meuser, K.T. & Doonan, R. (1997). Physical attractiveness in schizophrenia: The mediating role of social skill. *Behaviour Modification,* **21:** 78-85.

Penn, D.L., Kommana, S., Mansfield, M. & Link, B.G. (1999). Dispelling the stigma of schizophrenia: II. The impact of information on dangerousness. *Schizophrenia Bulletin,* **25:** 437-446

Penn, D.L., Kohlmaier, J.R. & Corrigan, P.W. (2000). Interpersonal factors contributing to the stigma of schizophrenia: social skills, perceived attractiveness and symptoms. *Schizophrenia Research,* **45:** 37-45.

Phelan, J.C., Bromet, E.J. & Link, B.G. (1998). Psychiatric illness and family stigma. *Schizophrenia Bulletin*, 24: 115-126

Phelan, J.C., Link, B.G., Stueve, A., Pescosolido, B. (2000). Public conceptions of mental illness in 1950 and 1996: What is mental illness and is it to be feared. *Journal of Health and Social Behavior,* **41:**188-207.

Philo, G. (1994). Media images and popular beliefs. *Psychiatric Bulletin,* **18:** 173-174.

Royal College of Psychiatrists (2000). *Every Family in the Land.* www.stigma.org.

Rahav, M. (1987). Public images of the mentally ill in Israel. *International Journal of Mental Health,* **15:** 59-69.

Read, J. & Harre, N. (2001). The role of biological and genetic causal beliefs in the stigmatisation of 'mental patients'. *Journal of Mental Health,* **10:** 223-235.

Read, J. & Baker, S. (1996). *Not Just Sticks and Stones: A survey of the stigma, taboos and discrimination experienced by people with mental health problems.* London. MIND.

Robert Wood Johnson Foundation (1990). *Public Attitudes Toward People with Chronic Mental Illness.* The Robert Wood Johnson Foundation program on chronic mental illness. New Jersey.

Robinson, E.A.R. (1996) Causal attributions about mental illness: Relationship to family functioning. *American Journal of Orthopsychiatry*, **66**(2): 282-295.

Rosenfield S. (1997). Labeling mental illness: The effects of received services and perceived stigma on life satisfaction. *American Sociological Review,* **62:**660-672.

Rothaus, P., Hanson, P.G., Cleveland, S.E. & Johnson, D.L. (1963). Describing psychiatric hospitalization: A dilemma. *American Psychologist,* **18:** 85-89.

Ryan, C.S. & Judd, C.M. (1992). False consensus and out-group homogeneity: A methodological note on their relationship. *British Journal of Social Psychology,* **31:** 269-285.

Ryder, A.G., Bean, G. & Dion, K.L. (2000). Caregiver responses to symptoms of first-onset psychosis: A comparative study of Chinese and Euro-Canadian families. *Transcultural Psychiatry,* **37:** 255-265

Sarbin, T.R. & Mancuso, J.C. (1970). Failure of a moral enterprise: Attitudes of the public toward mental illness. *Journal of Consulting and Clinical Psychology,* **35:** 159-173.

Sayce, L (2000). *From Psychiatric Patient to Citizen: Overcoming Discrimination and Social Exclusion.* New York, US: St Martin's Press, Inc.

Sayce, L. & Measey, L. (1999). Strategies to reduce social exclusion for people with mental health problems. *Psychiatric Bulletin*, **23**: 65-67

Sayce L. (1998). Stigma, discrimination and social exclusion: what's in a word? *Journal of Mental Health,* **7**:331-343.

Scheff, T.J. (1966). *Being Mentally Ill: A Sociological Theory.* Chicago, US. Aldine de Gruyter.

Segal, S.P., Kotler, P.L. & Holschuh, J. (1991). Attitudes of sheltered care residents toward others with mental illness. *Hospital and Community Psychiatry,* **42:**1138-1143.

Sharma, V, Murthy, S., Kumar, K., Agarwal, M. & Wilkinson, G. (1998). Comparison of people with schizophrenia from Liverpool, England, and Sakalwar-Bangalore, India. *International Journal of Social Psychiatry,* **44**: 225-230

Skinner, L.J., Berry, K.K., Griffith, S.E. & Byers, B. (1997). Generalizability and specificity of the stigma associated with the mental illness label: A reconsideration twenty-five years later. *Journal of Community Psychology,* **23:** 3-17

Stafford M.C. & Scott, R.R. (1986). Stigma deviance and social control: Some conceptual issues. In S.C Ainlay, G. Becker, and L.M. Coleman (Eds), *The Dilemma of Difference*. New York: Plenum.

Taylor, S.M. & Dear, M.J. (1980). Scaling community attitudes toward the mentally ill. *Schizophrenia Bulletin,* **7:** 225-240.

UKDoH (1994). *Health of the Nation Key Area Handbook. Mental Illness.* 2nd edition. London. HMSO.

UKDoH, (1999a). *A National Service Framework for Mental Health.* London. HMSO.

UKDoH (1999b). *General Public Attitudes to Mental Health/Illness.* COI ref:RS4206. London. Central Office of Information.

UKDoH (2001). *Mind out for Mental Health*. London. DoH Circulars.

UKNHSE (1996). *Burdens of Disease: A Discussion Document.* NHSE. London.

USDHSS (1999). *Mental Health: A report of the Surgeon General.* Washington D.C. US Department of Health and Human Services.

Wahl, O.F (1995). *Media madness: Public images of mental illness.* New Brunswick, N.J. Rutgers University Press.

Wahl, O.F. & Harman, C.R. (1989). Family views of stigma. *Schizophrenia Bulletin.* **15:** 131-139

Wahl, O.F. (1999). Mental health consumers' experience of stigma. *Schizophrenia Bulletin,* **25:** 467-478.

Wahl, O.F. (1992). Mass media images of mental illness: a review of the literature. *Journal of Community Psychology,* **20:** 343-352.

Wang, P.S., Demler, O. & Kessler, R.C. (2002). Adequacy of treatment for serious mental illness in the United States. *American Journal of Public Health,* **92**(1): 92-8.

Warner, R. (2000). *The Environment of Schizophrenia: Innovations in Practice, Policy and Communications*. Philadelphia, US. Brunner-Routledge.

Warner, R., Taylor, D., Powers, M. & Hyman, J. (1989). Acceptance of the mental illness label by psychotic patients: Effects on functioning. *American Journal of Orthopsychiatry,* **59:** 398-409

Warner, R. (1984). *Recovery from Schizophrenia: Psychiatry and Political Economy,* New York. Routledge.

Warner, R. (1999). Schizophrenia and the environment: Speculative interventions. *Epidemiologia e Psichiatria Sociale,* **8:** 19-34.

Wearden, A.J., Tarrier, N., Barrowclough, C., Zastowny, T.R. & Armstrong-Rahill, A. (2000). A review of expressed emotion research in health care. *Clinical Psychology Review,* **20:** 633-666.

Weisman, A., Lopez, S.R., Karno, M. & Jenkins, J. (1993). An attributional analysis of expressed emotion in Mexican-American families with schizophrenia. *Journal of Abnormal Psychology,* **102:** 601-606.

Weisman, A., Neuchterlein, K.H., Goldstein, M.J. & Snyder, K. (1998). Expressed emotion, attributions, and schizophrenia symptom dimensions. *Journal of Abnormal Psychology,* **107:** 355-359.

Weisman, A. & Lopez, R. (1997). An attributional analysis of emotional reactions to schizophrenia in Mexican and Anglo-American cultures. *Journal of Applied Social Psychology,* **27:** 223-244.

Weisman A., Neuchterlein, K.H., Goldstein, M.J. & Snyder, K. (2000). Controllability perceptions and reactions to symptoms of schizophrenia: A within-family comparison of relatives with high and low expressed emotion. *Journal of Abnormal Psychology,* **109:** 167-171.

Wright, E.R., Gronfein, W.P.& Owens, T.J. (2000). Deinstitutionalization, social rejection, and the self-esteem of former mental patients. *Journal of Health and Social Behavior,* **41:** 68-90

Wilmouth, G.H., Silver, S. & Severy, L.J. (1987). Receptivity and planned change: Community attitudes and deinstitutionalisation. *Journal of Applied Psychology,* **72:** 138-145.

Wilson, C., Nairn, R., Coverdale, J. & Panapa, A. (2000). How mental illness is portrayed in children's television: A prospective study. *British Journal of Psychiatry,* **176**: 440-443.

Yarrow, M., Clausen, J. & Robbins, P. (1965). The social meaning of mental illness. *Journal of Social Issues,* **11:** 33-48.

Zullow, H.M., Oettingen, G., Peterson, C., & Seligman, M.E. (1988). Pessimistic explanatory style in the historical record: LBJ, presidential candidates, and East versus West Berlin. *American Psychologist,* **43:** 673-682.

CHAPTER 2

Brief Paper

Representations of Schizophrenia held by patients, their parents and members of the general public: Points of convergence, divergence and relationships with dimensions of stigma.

Summary

Background – Differences in the representations of schizophrenia held by patients and others have been suggested to play a role in the experience of stigma. However, little is known about the most common areas of divergence in representations between patients and their parents, and whether and to what extent such a divergence in representations are associated with perceptions of stigma or responses to stigma.

Objective – The purpose of the present study was to examine representations of psychosis held by patients and their carers (parents) and to examine their association with dimensions of the stigma experience. A small control sample of the general public was also employed for comparative purposes.

Method – Cross sectional design. Patients, their parents and members of the general public completed a measure of representations of psychosis. Patients also completed an additional measure of dimensions of stigma.

Results – Members of the general public did not have a uniformly negative representation of psychosis. They did perceive patients to have less coherence or understanding about their condition and to experience a wider range of symptoms compared with patients or carers. Members of the general public scored higher than carers on beliefs in the effectiveness of medical treatments, and lower on perceptions of severity of consequences than carers or patients. Patients whose carers held a stronger belief in (maximised) the potential for chronicity of psychosis reported more stigma and tended to use secrecy as a means of dealing with stigma. Greater minimization of the consequences by carers was associated with greater social withdrawal by patients. Patients whose carers minimized beliefs about the level of personal control that the patient could exercise over their condition reported significantly less preventive telling in response to stigma. Partial correlations demonstrated that the manner in which patients responded to stigma was affected by patient-carer differences in the severity of consequences, differences in ideas about how much control patients can exercise over their condition, and differences in representations about the course of psychosis.

Conclusion - Dissimilarity in particular aspects of representations of psychosis held by patients and their carers is associated with dimensions of 'felt' stigma and patients' responses to stigma. The findings of this pilot study add to the literature on the importance of concordance between patient and carer models of illness.

Introduction

Previous research has demonstrated that beliefs about illness held by significant others may have important ramifications for the well-being of patients (e.g., Coyne, Wortman & Lehman, 1988). Much of this research has concentrated on attributions about causes of psychosis either in relatives (Brewin, McCarthy, Duda & Vaughan, 1991) or in healthcare professionals (Metha & Farina, 1997). However, social cognition models suggest that beliefs about illness take a form that is broader than simple attributions about causation of symptoms (Leventhal, Nerenz & Steele, 1984; Heijmans, DeRidder & Bensing, 1999), and this representational model has begun to be examined in psychosis (Barrowclough Lobban, Hatton & Quinn, 2001).

The use of social cognition models has been given added importance in recent years and researchers have demonstrated the importance of meaning making in adjustment to severe mental illness (Barker, Lavender & Morant, 2001; Barrowclough et al, 2001; Roe, 2001). This common-sense model is said to be oriented around a number of dimensions of experience: (i) beliefs about illness identity (symptoms), (ii) chronicity or recurrence of the condition, (iii) consequences, (iv) personal and treatment control, (v) illness coherence, (vi) causes of the condition and (vii) patients emotional response to their condition. Social cognition frameworks have been applied in an attempt to predict the development of discriminatory behaviours and stigma towards people with severe mental illness with a good deal of success (Boisvert & Faust, 1999; Corrigan,

Backs-Edwards, Green, Lickey-Diwan & Penn, 2001; Yanos, Rosenfeld, & Horowitz, 2001).

Much of current research into the correlates of stigma underscores the importance of social cognitive factors in stigma (e.g., Read & Harre, 2001; Corrigan & Watson, 2002; Metha & Farina, 1997). Social cognition has also been used as a means to understand the development of lay beliefs about severe mental illness in the general public (Angermeyer & Matschinger, 1995; Furnham & Bower,1992; Wahl, 1995). Much less work, however, has been conducted examining such lay beliefs, or representations of psychosis, within the family and the potential effects of differences between patient-relative representations and dimensions of 'felt' or perceived stigma.

It has been demonstrated that there are three main ways in which patients deal with the stigma of severe mental illness (Link, Mirotznik and Cullen, 1991; Link, Struening, Rahav, Phelan, & Nuttbrock, 1997; Phelan, Bromet & Link, 1998). These responses tend to take the form of *secrecy;* where people decide to conceal their treatment history from employers, relatives or intimate partners to avoid rejection (Goffman, 1963; Jones, Farina, Hastorf, Markus, Miller, & Scott, 1984), *selective avoidance or withdrawal,* where people limit social interaction to those who know about and tend to accept one's stigmatised condition; and *preventive telling* in the hope of enlightening others so as to ward off negative attitudes. Link, Mirotznik and Cullen (1991), reported that these responses to

stigma can be stigmatising in themselves and tend to be associated with unemployment and demoralization in patients.

The purpose of this study was to investigate the representations of psychosis held by a sample of patients and their principal carers, and to contrast these representations with the model held by members of the general public. A second aim was to assess the relationship between divergent patient-carer representations and patient's perceptions of stigma and responses to stigma. The hypotheses to be tested were that greater divergence between patient and carer representations of psychosis would be associated with higher patient-report of stigma, secrecy, preventive telling and withdrawal. A second hypothesis was that members of the general public who had no direct experience of people with psychosis would have a more hopeless or 'engulfing' representation of psychosis. Thus members of the general public would score higher than either patients or carers on beliefs in chronicity, and in its relapsing-remitting nature, they would perceive a stronger illness identity, have less confidence in medical treatments, perceive the consequences to be more severe, would have weaker beliefs in patients personal control over the illness, lower illness coherence, and perceive patients to have weaker emotional representations.

Method

Sixteen patient-parent dyads and 16 members of the general public from the same geographical region were recruited to the study. Members of the general public were interviewed in their own homes and these participants had no direct contact or experience of persons with a severe mental illness diagnosis.

Patients being cared for by Worcestershire mental health services who were not experiencing a frank exacerbation of psychosis and who expressed a wish to participate in response to an information sheet provided by key workers, were asked to identify the person who had most interaction with them or who adopted the key care-taking responsibility. In all cases the person chosen as principal carer was a parent. Named carers were contacted and asked if they wished to participate in the study. All participants completed their assessments independently of each other. The study was approved by Worcestershire Local Research Ethics Committee.

Patient and parent representations

Participants completed an appropriately re-worded revised Illness Perception Questionnaire – IPQ-R (Moss-Morris, Weinman, Petrie, Horne, Cameron, & Buick *in press*). This is a 38 item scale which assesses participants beliefs in the course of schizophrenia (timeline – 6 items; timeline cyclical - 4 items), its perceived consequences (6 items), patients personal control over it (6 items), confidence in treatment control (5 items), illness coherence (5 items), emotional

representations (6 items), and Illness identity or the symptoms participants associate with their experience of psychosis (27 core items). As the identity subscale of the IPQ consists of symptoms that have little relevance to psychosis, items from the SANS and SAPS (Andreasen, Arndt, Miller, Flaum, & Nopoulos, 1995; Toomey, Kremen, Simpson, Samson, Seidman, Lyons, Faraone, & Tsuang, 1997) were employed. Participants could also cite symptoms that were not included in the measure. An adjusted score (sum of scale items divided by number of items) is calculated with a possible maximum of 5 for each sub-scale with the exception of the Illness identity scale (maximum 27).

Dimensions of Stigma

Patients also completed the measure of stigma dimensions developed by Link Mirotznik and Cullen (1991). This includes a 12 item measure of stigma (devaluation and discrimination), and a measure of responses to stigma incorporating scales on secrecy (5 items), withdrawal (5 items), and preventive telling (7 items). In the discrimination/devaluation measure, participants are asked to indicate the extent of their agreement with each of 12 items. Scores range from 1 'strongly agree' to 6 ' strongly disagree'. This scale has previously been demonstrated to have good internal consistency *(alpha=0.82)*. The secrecy, withdrawal and education scales are scored using the same Likert scale as the discrimination/devaluation measure. Alphas of 0.71, 0.67 and 0.71 have been reported for secrecy, withdrawal, and preventive telling respectively (Link, Mirotznik & Cullen, 1991).

Statistical Analysis

One-way ANOVA was used to investigate general differences between patient carer and general public perceptions of psychosis. Descriptive statistics and Chi Square test were calculated to provide a qualitative impression of areas of possible divergence between patients and parents on the individual representations of causes and symptoms. Pearson's and partial correlations were carried out between dissimilarity scores on the IPQ-R and stigma dimensions.

Results

Patients were aged between 21 and 38 years (mean=29.6 SD=4.4). Just over half (56%; n=9) were male and had a mean duration of psychosis of 4.6 years (SD=2.2). Age at onset ranged from 19 to 31 years and patients had a mean of 4 episodes (SD=3.5). Distribution of the number of episodes experienced by patients was skewed and therefore a log transformation was undertaken to normalize the distribution. This transformed 'number of episodes' variable was used in all subsequent analyses. Cronbach's α for Discrimination, Secrecy, Preventive Telling, and Withdrawal were 0.90, 0.74, 0.62, and 0.91 respectively.

The ages of parents ranged from 42 to 72 years (mean=56, SD=8.6), and 75% (n=12) were female. Members of the general public had a narrower age range of between 21 and 44 years (mean=32, SD=8.1) and 56% (n=9) were female.

General Differences between patients, relatives and general public perceptions about psychosis

Table 1 shows the scores on the representations of psychosis for patients, carers and members of the general public.

Table 1. Mean (SD) scores and Cronbach's alpha for patients, carers and members of the general public's representations of psychosis

Representations	Patient	Carer	General Public
Illness Identity			
Mean (SD)	14.41 (4.33)	15.03 (8.61)	22.64 (9.60)
Alpha	.76	.95	.68
Time Line			
Mean (SD)	3.22 (.58)	3.37 (.65)	3.58 (.25)
Alpha	.72	.69	.61
Consequences			
Mean (SD)	4.09 (.34)	4.68 (.24)	4.42 (.24)
Alpha	.63	.64	.68
Personal Control			
Mean (SD)	3.77 (.79)	3.67 (.67)	3.48 (.36)
Alpha	.89	.90	.89
Treatment Control			
Mean (SD)	4.03 (.41)	3.28 (.48)	3.72 (.30)
Alpha	.84	.64	.69
Illness Coherence			
Mean (SD)	3.08 (.83)	3.00 (.86)	2.07 (.37)
Alpha	.82	.91	.85
Time-line Cyclical			
Mean (SD)	2.98 (.88)	2.95 (.64)	3.59 (.37)
Alpha	.78	.62	.66
Emotional Representations			
Mean (SD)	3.82 (.69)	4.00 (.41)	3.71 (.27)
Alpha	.66	.69	.58

PAGE

MISSING

IN

ORIGINAL

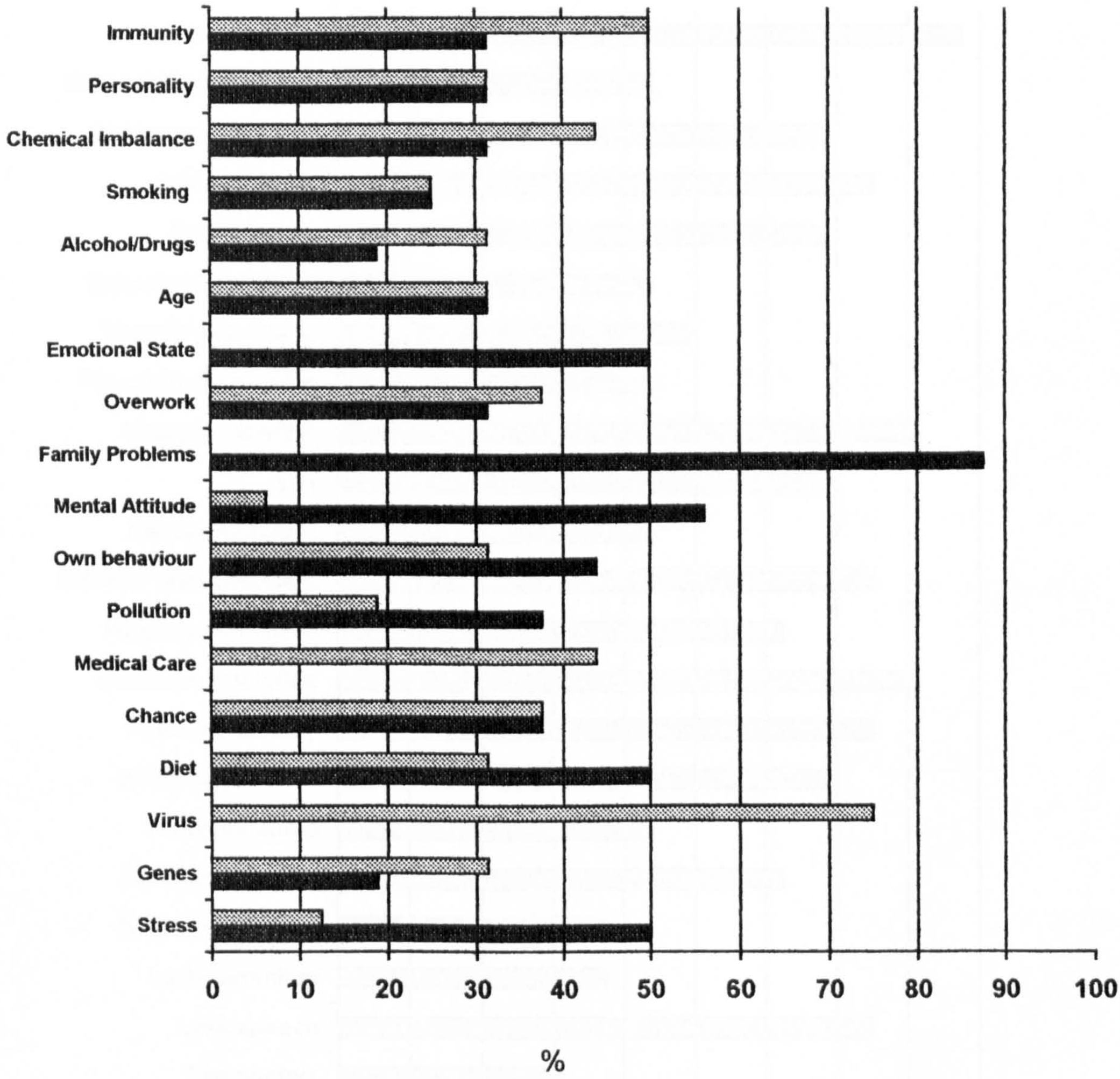
from the patient's representation. Carers' scores which were less than the patients on particular representations were termed 'minimising' and carers' scores which were greater than the patient's on representations were termed 'maximising'. All subsequent correlations were computed using these dissimilarity scores.

Representations of Causes

Using patients' views of causal attributions as the criterion, carers' scores were compared against this criterion and ranked in terms of agreement, minimization and maximisation for individual cause items. Figure 1 shows the percentage of patient-parent dyads minimising and maximising on individual causes.

Carers tended to minimise an aetiological role for stress, diet, pollution, patient's mental attitude, patient's own behaviour, and family problems relative to patients, and maximised hereditary factors, virus, poor medical care, and alcohol or drug misuse as potential causes of their offspring's schizophrenia. The proportion of relatives who maximized particular causes relative to patients was significant only for virus (X^2=4.0, p=0.04). Similarly, statistical significance was evident only in relation to parents minimizing causes as being due to patients' mental attitude (X^2= 6.1, p=0.04) and family problems (X^2=9.0, p=0.01) relative to patients' representations of causes.

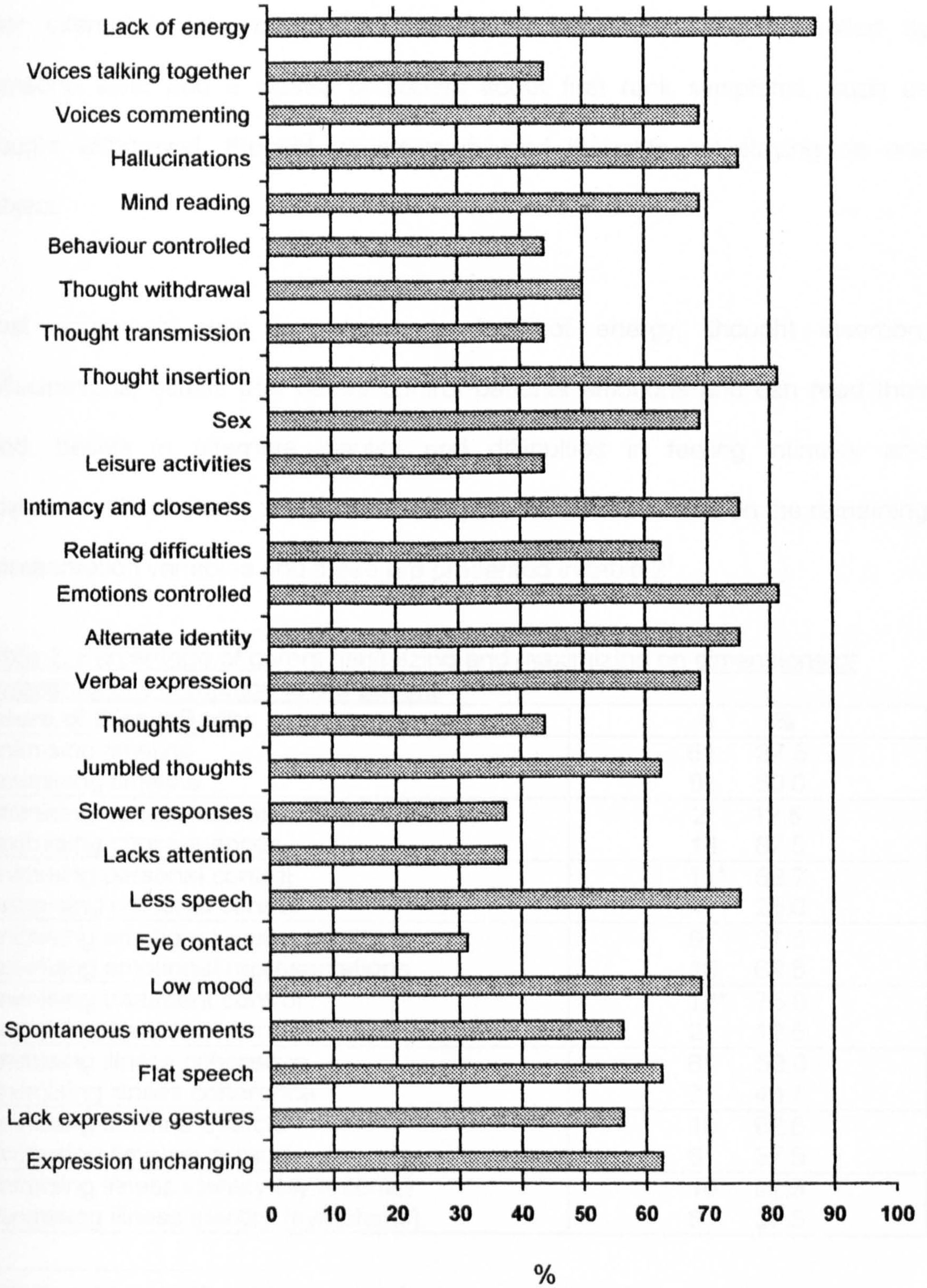
Figure 1. Percentage of patient-parent dyads minimizing ■ and maximizing ▩ individual causal beliefs about causes of schizophrenia.



Representations of Psychosis Identity

Participants' level of agreement on individual psychosis identity items (symptoms or experiences attributed to psychosis) was also examined (Figure 2).

Figure 2 - Percentage of patient-carer dyads showing consensus on individual symptoms (Identity)



Symptoms where there was least agreement between patients and carers was in relation to deficits in patient's eye contact, inattention, slowness of response, poor interest in leisure activities, beliefs in behaviour being controlled by someone else, and a cluster of beliefs about first rank symptoms, such as thought withdrawal, thought transmission, and thoughts not staying on one subject.

Most agreement was in relation to lack of energy, thought insertion, hallucinations, beliefs that others control patients emotions and can read their mind, beliefs in alternate identity and difficulties in feeling intimacy and closeness. Dissimilarity scores were computed for scale scores on the remaining representation variables and these are presented in table 2[1].

Table 2. Percentage of carers minimizing and maximizing on dimensions of representations in relation to the patient

Nature of Dissimilarity	n	%
Minimising timeline	6*	37.5
Maximising timeline	8	50.0
Minimising consequences	2	12.5
Maximising consequences	14	87.5
Minimising personal control	11*	68.7
Maximising personal control	4	25.0
Minimising emotional representations	6	37.5
Maximisng emotional representations	10	62.5
Minimising treatment control	12*	75.0
Maximising treatment control	2	12.5
Minimising illness coherence	8*	50.0
Maximising illness coherence	7	43.7
Minimising timeline cyclical	10	62.5
Maximising timeline cyclical	6	37.5
Minimising illness identity (symptoms)	10	62.5
Maximising illness identity (symptoms)	6	37.5

[1] * n's do not sum to 16 on all measures due to agreement on these subscales

Chi square test showed significant differences in the proportion of carers maximising severity of consequences of psychosis for the patient *(X^2=9.0, p=0.003)*, minimising the patient's agency or ability to control aspects of the condition *(X^2=9.87, p=0.007)*, and having significantly less confidence in treatment cure or control *(X^2=12.5, p=0.002)*.

Associations between dissimilarity scores and stigma

Correlations were computed between patients' and carers' dissimilarity scores, and patients' scores on the stigma dimensions of discrimination, secrecy, preventive telling and withdrawal (table 2)

When dissimilarity was high due to carers having weaker beliefs that the condition would be of short duration, when they maximized patients' personal control and minimized consequences, patients reported greater stigma. Coping with stigma through withdrawal was associated with increased minimization of the consequences by carers. Patients' response to stigma through preventive telling was also associated with carers having a stronger belief than patients in the level of personal control that the patient could exercise over their condition.

Associations between stigma and responses to stigma

As there were associations between the dimensions of stigma and a number of representations of psychosis (table 2), partial correlations were undertaken with the patient-carer differences in representations of the course of psychosis (time-

line and timeline cyclical), beliefs in personal control, and consequences statistically controlled.

Controlling for differences in perceptions about the severity of consequences, the partial correlation for the relationship between stigma and withdrawal was no longer significant *(r=.24, p=.27)*. When differences in the representations of personal control were partialled out, the correlation between stigma and preventive telling fell below the criterion for significance *(r=.31, p=.16)*. Thus differences in ideas about how much control the patient can exercise over the condition is implicated in whether patients use preventive telling to deal with their perceptions of stigma

When differences in time-line was controlled, the correlation between stigma and preventive telling failed to reach significance *(r=.27, p=.21)*, while the association with secrecy remained essentially the same *(r=.84)*. Finally, partialling out differences in ideas about the relapsing remitting course of the condition (time-line cyclical) increased the strength of the relationship between stigma and preventive telling *(r=.51)*. Taken together the results of the partial correlations suggest that differences in these particular representations held by patients and carers play an important role in affecting the nature of the relationship between stigma and patients use of secrecy, withdrawal, and preventive telling as a means of dealing with stigma.

Table 3. Pearson's correlations between clinical history, dissimilarity scores for dimensions of psychosis representations and aspects of Stigma.

		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1	Stigma															
2	Secrecy	**.87****														
3	Preventive Telling	**.43****	**.46****													
4	Withdrawal	**.38***	.24	**-.42***												
5	Age of patient	.06	.08	-.05	-.05											
6	Age at onset	.07	.13	.28	**-.50****	**.82****										
7	Duration with psychosis	.15	-.02	-.20	.20	**.41***	-.19									
8	Time-Line	**-.39***	**-.40***	-.30	.27	-.09	**-.38***	.20								
9	Consequences	**.41***	.15	-.01	**.44****	-.10	**-.39***	.27	.25							
10	Personal Control	**-.42***	-.14	**-.40***	-.11	.08	.09	**.48****	-.01	-.09						
11	Emotional Representations	-.25	-.19	-.17	-.05	.05	-.23	-.12	.09	-.01	-.03					
12	Treatment Control	.12	.19	-.10	-.11	.10	.26	-.18	**-.39***	.16	**.42***	.17				
13	Illness Coherence	-.29	-.13	-.18	.04	-.01	-.22	**-.47****	.16	-.29	**-.38***	**.54****	.01			
14	Time Line-Cyclical	**.49****	**.39***	.19	.28	-.13	-.10	-.08	-.08	**.71****	-.31	.29	.32	**-.40***		
15	Identity	-.12	-.25	-.26	.32	-.10	**-.65****	**.38***	**.71****	**.44****	.20	**.39***	-.23	.08	-.13	
16	Number of Episodes	**.49****	**.40***	.11	**.43****	-.15	**-.42***	**.47****	.01	**.41***	.19	.08	-.12	-.21	.01	.25

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

Discussion

This study set out to examine the areas of dissimilarity between the representations of psychosis held by patients and their parents and to contrast these representations with the model held by members of the general public. This study also aimed to investigate the association between divergent patient-carer representations and patients perceptions of stigma and their response to stigma.

Members of the general public's representations tended to be more negative than patients or carers, particularly in relation to whether and to what extent the condition made sense to the patient, and also in relation to the nature of symptoms perceived as being part of schizophrenia. However, carers rated psychosis as having more severe consequences for the patient than either patients or members of the general public, and they also reported significantly less confidence in medical interventions for the management of psychosis.

In terms of the areas of agreement and disagreement between patients and carers, there was some consensus on symptoms experienced and causes of psychosis. However, differences were evident particularly in relation to patients having a stronger view of the role of family problems and their own mental attitude as potential causes of schizophrenia. For carers, the potential role of pathogens (virus) was significantly more important as a potential cause than it was for patients.

Minimisation of representations by carers did not necessarily have a positive impact on adaptive outcome, possibly because it may give patients the impression of not being taken seriously. The findings in relation to stigma and differences in patient-carer representations are congruent with previous research which has shown that beliefs held by the general public particularly in relation to chronicity and recurrence of schizophrenia and responsibility or control appraisals tend to be associated with stigma (Furnham & Bower, 1992; Warner, 2000). It is unsurprising that a majority of people with a diagnosis of schizophrenia choose to keep their diagnosis a secret (Wahl, 1995; Link et al 1991) and in this study patients whose carers maximised chronicity were more likely to adopt secrecy as a response to the potential stigma of their condition. Similarly withdrawal, which is a robust predictor of chronicity of psychosis (Myin-Germeys, van Os, Schwartz, Stone & Delespaul, 2001; Kay, 1991), was associated with divergent patient-carer representations of the severity of consequences of psychosis.

The association between the mismatch in patient-parent perceptions of patients personal control over their psychosis and patients use of preventive telling is an interesting finding which may have implications for research into how people decide who they will disclose to, and when, or if they will disclose at all (Roe, 2001). There is compelling evidence from previous research demonstrating that family members who perceive the patient to have greater control over the symptoms of schizophrenia tend to express greater negative emotions, such as

anger and annoyance towards the patient (e.g., Wearden, Tarrier, Barrowclough, Zastowny & Armstrong-Rahill, 2000). In this respect, it is not surprising that patients whose carers believe that they have more control over their psychosis would be less likely to deal with stigma through attempting to enlighten others so as to ward off negative attitudes.

There are some limitations of the current study that need to be addressed. Firstly, the sample was small and highly selected and thus may not be entirely representative of patients and parents living with schizophrenia. Secondly, there may be methodological implications of using patients' representations as the criterion against which carers' scores were taken as an indicator of maximisation or minimisation. Nonetheless, patients were not experiencing a frank exacerbation of psychosis, and there is substantial evidence that patients in remission or with residual symptoms are able to provide cogent accounts of their experiences which are stable over time and which tend to be consistent with external observations (Barrowclough, Haddock, Lowens, Connor, Pidiswji, & Tracey, 2001; Cutting & Dunne, 1989; Scazufca, Kuipers & Menezes, 2001). More research is clearly warranted on the impact of similarity and dissimilarity in patient-carer representations of psychosis.

The findings of this pilot study have demonstrated that dissimilarity between aspects of the representations of psychosis held by patients and their parents may have implications for 'felt' stigma and responses to stigma in patients

diagnosed with schizophrenia. However there is clearly further work to refine the measure of representations before it can be described as a measure of the personal model of psychosis. Nonetheless, there may be added value of using such representations as measures of outcome from interventions which aim to develop a working narrative between the patient and other members of their family, such as Behavioural Family Therapy, or as an aid to assessing the potential for mismatch between patients and healthcare professionals.

In conclusion, the results of this study do not permit any direct statements to be made on mediation by divergent patient-carer representations. Nonetheless, it is clear that divergent representations about the potential course of schizophrenia, the severity of its consequences, and ideas about how much personal control patients can exercise over the sequelae of their condition may affect the nature of the relationship between patients' perception of stigma and aspects of their responses to it.

References

Andreasen, N.C., Arndt, S., Miller, D., Flaum, M. & Nopoulos, P. (1995). Correlational studies of the scale for the assessment of negative symptoms (SANS) and the scale for the assessment of positive symptoms (SAPS): an overview and update. *Psychopathology*, **28: 7-17.**

Angermeyer, M.C. & Matschinger, H. (1995). Violent attacks on public figures by persons suffering from psychiatric disorders: Their effect on the social distance towards the mentally ill. *European Archives of Psychiatry and Clinical Neuroscience*, **245**: 159-164

Barker, S., Lavender, T., & Morant, N. (2001). Client and family narratives on schizophrenia. *Journal of Mental Health*, **10**: 199-212

Barrowclough, C., Haddock, G., Lowens, I., Connor, A., Pidiswji, J., & Tracey, N. (2001). Staff expressed emotion and causal attributions for client problems on a low security unit: an exploratory study. *Schizophrenia Bulletin*, **27:** 517-526.

Barrowclough, C., Lobban, F., Hatton, C. & Quinn, J. (2001). An investigation of models of illness in carers of schizophrenia patients using the Illness Perception Questionnaire. *British Journal of Clinical Psychology*, **40:** 371-385.

Boisvert, C.M. & Faust, D. (1999). Effects of the label 'schizophrenia' on causal attributions of violence. *Schizophrenia Bulletin*, **25:** 479-491.

Brewin, C.R., McCarthy, B., Duda, K. & Vaughan, C.E. (1991). Attribution and expressed emotion in the relatives of patients with schizophrenia. *Journal of Abnormal Psychology*, **100:** 546-554.

Corrigan, P.W., Backs-Edwards, A., Green, A., Diwan, S.L., Penn, D.L. (2001). Prejudice, social distance, and familiarity with mental illness. *Schizophrenia Bulletin*, **27:** 219-225.

Corrigan, P.W. & Watson, A.C. (2002). The paradox of self-stigma and mental illness. *Clinical Psychology: Science and Practice*, **9:** 35-53.

Coyne, J.C., Wortman, C.B. & Lehman, D.R. (1988). The other side of support. Emotional involvement and miscarried helping. In B.H. Gottlieb (Ed.), *Marshalling Social Support: Formats Processes and Effects.* (pp305-330). Newbury Park. Sage Publications

Cutting, J. & Dunne, F. (1989). The subjective experience of schizophrenia. *Schizophrenia Bulletin*, **15: 217-231.**

Furnham, A. & Bower, P. (1992). A comparison of academic and lay theories of schizophrenia. *British Journal of Psychiatry*, **161:** 201-210.

Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity.* Englewood cliffs, N.J. Prentice Hall.

Heijmans, M., DeRidder, D. & Bensing, J. (1999). Dissimilarity in patients and spouses representations of chronic illness: Exploration of relations to patient adaptation. *Psychology and Health*, **14:** 451-466.

Jones, E., Farina, A., Hastorf, A., Markus, H., Miller, D.T. & Scott, R. (1984). *Social Stigma: The Psychology of Marked Relationships.* New York. Freeman.

Kay, S.R (1991) *Positive and Negative Syndromes in Schizophrenia: Assessment and Research.* New York. Brunner Mazel.

Leventhal, H., Nerenz, D.R. & Steele, D. (1984). Illness representations and coping with health threats. In A. Baum & J. Singer (Eds). *Handbook of Psychology and Health.* (pp229-252), Hillsdale, N.J. Erlbaum.

Link, B.G., Struening, E.L., Rahav, M., Phelan, J.C. & Nuttbrock, L. (1997). On stigma and its consequences: evidence from a longitudinal study of men with dual diagnoses of mental illness and substance abuse. *Journal of Health and Social Behaviour*, **38:** 177-190.

Link, B.G, Mirotznik, J. & Cullen, F.T (1991). The effectiveness of stigma coping orientations: Can negative consequences of mental illness labeling be avoided. *Journal of Health and Social Behaviour*, **32:** 302-320.

Mehta, S. & Farina, A. (1997). Is being "sick" really better? Effect of the disease view of mental disorder on stigma. *Journal of Social and Clinical Psychology*, **16:** 405-419.

Moss-Morris, R., Weinman, J., Petrie, K.J., Horne, R., Cameron, L.D. & Buick, D. The revised Illness Perception Questionnaire (IPQ-R) (2002).. *Psychology and Health*, **17:** 1-16.

Myin-Germeys, I., van Os, J., Schwartz, J.E., Stone, A.A. & Delespaul, P.A. (2001). Emotional reactivity to daily life stress in psychosis. *Archives of General Psychiatry*, **58:** 1137-1144.

Phelan, J.C., Bromet, E.J., & Link, B.G. (1998). Psychiatric illness and family stigma. *Schizophrenia Bulletin*, **24:** 115-126

Read, J. & Harre, N. (2001). The role of biological and genetic causal beliefs in the stigmatisation of 'mental patients'. *Journal of Mental Health*, **10:** 223-235.

Roe, D. (2001). Progressing from patienthood to personhood across the multidimensional outcomes in schizophrenia and related disorders. *Journal of Nervous and Mental Disease,* **189:** 691-699.

Scazufca, M., Kuipers. E. & Menezes, P.R. (2001). Perception of negative emotions in close relatives by patients with schizophrenia. *British Journal of Clinical Psychology,* **40:** 167-175.

Toomey, R., Kremen, W.S Simpson, J.C., Samson, J.A., Seidman, L.J., Lyons, M.J., Faraone, S.V. & Tsuang, M.T. (1997). Revisiting the factor structure for positive and negative symptoms: Evidence from a large heterogeneous group of psychiatric patients. *American Journal of Psychiatry,* **154:** 371-377.

Wahl, O.F. (1995). *Media Madness: Public Images of Mental Illness.* New Brunswick, US: Rutgers University Press.

Warner, R. (2000). *The Environment of Schizophrenia: Innovations in Practice, policy and communications.* Philadelphia, US: Brunner-Routledge.

Wearden, A.J., Tarrier, N., Barrowclough, C., Zastowny, T.R. & Armstrong-Rahill, A. (2000). A review of expressed emotion research in health care. *Clinical Psychology Review,* **20:** 633-666.

Yanos, T., Rosenfeld, S. & Horowitz, A.V. (2001). Negative and supportive social interactions and quality of life among persons diagnosed with severe mental illness. *Community Mental Health Journal,* **37:** 405-419.

CHAPTER 3

Main Paper

Perceptions of Psychosis, Coping, Appraisals and Psychological Distress in the Relatives of Patients with Schizophrenia: A Self-Regulation Theory Analysis.

Summary

Objective. Following Leventhal's self regulation model, the purpose of the present study was to provide an examination of the relationship between psychosis perceptions, coping strategies, appraisals, and distress in the relatives of patients with schizophrenia.

Design. Cross sectional study.

Method. Forty two relatives of patients with schizophrenia completed the Hospital Anxiety and Depression Scale (HADS), a brief coping strategies measure (COPE), the Revised Illness Perception Questionnaire (IPQ-R), and a measure of primary and secondary appraisals (Family Questionnaire).

Results. In general, carers who viewed their relative's psychosis as chronic, who had a stronger illness identity (experience of symptoms), who held a stronger belief in the severity of its consequences, who reported weaker beliefs in treatment control but stronger beliefs that their relative could exert control over their condition had higher distress scores. Coping through seeking emotional support, the use of religion/spirituality and positive reframing were associated with less distress, while coping through self-blaming was associated with higher distress scores. Hierarchical regression demonstrated that illness perceptions, primary appraisals and coping accounted for significant variance in distress scores. Furthermore there was evidence that coping had a mediational role on distress. Use of more self-blaming and less use of positive reframing, and stronger beliefs that the individual could exert personal control over their condition and weaker beliefs in treatment control were significantly associated with distress in the final regression analyses.

Conclusion. Results provide partial but not unequivocal support for the self-regulation model in carers of people with a diagnosis of schizophrenia. Findings may invite us to consider the further use of the self regulation model as a framework for understanding distress in the carers of people with a diagnosis of schizophrenia.

Introduction

One of the most important consequences of current de-institutionalisation policies is that family members have become the principal caregivers for patients with psychosis (Cuijpers, 1999). Caring for a relative with psychosis is not without potential costs for family members (Baronet, 1999; Magliano, Fadden, Fiorillo, Malangone, Solrrentino, Robinson & Maj, 1999), and attention has been drawn to the danger that family members can be viewed solely as agents of rehabilitation and expected to cope unaided with difficulties that may prove substantial (Fadden, Bebbington & Kuipers, 1987; Schene, van Wijngaarden & Koeter, 1998; Smith & Birchwood, 1987; Tennakoon, Fannon, Doku, O'Ceallaigh, Soni, Santamaria, Kuipers, & Sharma, 2000). It is, therefore, unsurprising that levels of clinically-relevant distress ranging from 12% to 60% have been reported in relatives of patients diagnosed with schizophrenia (Barrowclough, Tarrier & Johnston, 1996; Fadden, Bebbington & Kuipers, 1987; Oldridge & Hughes, 1992; Smith, Birchwood & Cochrane, 1993). In order to account for such distress, some studies have attempted to adopt a stress and coping framework to investigate predictors of well-being or distress in relatives (Budd, Oles & Hughes, 1998; Provencher, Fournier, Perreault, Vezina, 2000; Solomon & Draine, 1995; Tennakoon, et al, 2000; Webb, Pfeiffer, Meuser, Gladis, Mensch, DeGirolamo, Levinson, 1998). For example, Webb and colleagues (1998) found that well-being was related to lowered frequency of symptoms and social support but not to coping style. Similarly, Barrowclough & Parle (1997), reported that of 10 clinical and demographic variables, primary appraisals was one of only two variables which significantly predicted relative's distress at admission to hospital.

While the stress and coping literature has provided some helpful findings on the impact of psychosis for family members, more recently, Leventhal's illness perception/self regulation model (Leventhal, Meyer & Nerenz 1980; Leventhal, Diefenbach & Leventhal 1992; Leventhal, Benyamini, Brownlee, Diefenbach, Leventhal, Patrick-Miller & Robitaille, 1997) has been touted as a useful model by which to understand the process and outcome of distress in the relatives of patients with schizophrenia (Barrowclough, Lobban, Hatton & Quinn, 2001).

The cognitive representation of illness can best be understood as "a person's own common-sense beliefs about illness" (Leventhal, Meyer & Nerenz, 1980). Cognitive representations about a condition are likely to be based on generic memorised information about health and illness, information patients will receive in the medical domain, and lay information from family and friends and from the wider media. The cognitive representation/self regulation model has received increased attention in recent years as evidence supporting the importance of interpretative processes between objective demands and subjective states has entered the literature as part of a general information processing approach to cognition and behaviour (e.g., Moss-Morris, Petrie & Weinman, 1996; Heijmans, 1999; Scharloo, Kaptein, Weinman, Hazes, Willems, Bergman, & Roojimans, 1998; Steed, Newman & Hardman, 1999).

The major attributes of Illness representation are oriented around a number of dimensions of experience: (i) beliefs about symptoms, (ii) chronicity or recurrence of the condition, (iii) consequences, (iv) personal control, (v) treatment control, (vi) illness coherence, (vii) causes of the condition and (viii) patients emotional response to their

condition.

In general terms, the model predicts that the representation held by an individual will influence their selection of coping strategies and the subsequent appraisal of their effectiveness. Processing is assumed to proceed along two parallel, yet integrated dimensions, which deal with processing the cognitive representation and processing the emotional representation. Thus, cognitive representations define targets for coping, with the result that coping and subsequent appraisal are assumed within the model to mediate the relationship between the cognitive representation and psychological outcome.

Cognitive models of adjustment, such as the self-regulation model, are predicated upon the assumption that people are active processors of information rather than passive objects upon which illness or other deleterious phenomena impact (Leventhal, Diefenbach & Leventhal, 1992). Active information processing is fundamental in enabling the construction of a coherent understanding of illness or experience. Emotional reactions and coping flow from the person's understanding of their relative's illness and appraisal of its threat (Leventhal et al, 1997).

Distress, therefore, may arise out of a dynamic interaction between beliefs held by the individual about their relative's condition, demands of an individual's environment and their coping abilities. Whether a particular event is perceived as stressful will depend on the individual appraising the event as beyond his/her coping capacity. Cognitive appraisal is integral to the self-regulation approach and consists of two sequential

forms: primary and secondary appraisal. Primary appraisal is the process of evaluating the personal meaning of the event in terms of its relevance, positiveness or stressfulness. If appraised as stressful, further processing is involved which may class the stressful event as threatening, harmful, or challenging. Secondary appraisal involves an active review of extant coping responses and an estimation of their chances of success or efficacy in coping with the stressor (Leventhal, Meyer & Nerenz, 1980).

The self regulation/cognitive representation model has been widely applied in patients with physical illness (Petrie & Weinman, 1997) and the principal measure of cognitive representations – the Illness Perception Questionnaire - has begun to be examined in work with patients with psychosis and their carers (Barrowclough, Lobban, Hatton & Quinn, 2001). Barrowclough and colleagues (2001) have demonstrated that greater perceived negative consequences for the patient was related to higher self reported distress in the carer. Interestingly, perceptions of severity of consequences and illness identity (symptoms) were the only illness perception variables to show significant correlations with distress. However, this study did not set out to provide a test of the self-regulation approach and therefore did not assess appraisals, coping strategies or causal beliefs, which are an integral part of the model and which will be examined in the current study.

The aim of the current study was to examine whether coping and appraisals are important in accounting for additional variance in psychological distress in carers of people with a diagnosis of schizophrenia, or whether the cognitive representation of

psychosis held by carers is adequate on its own. Specifically, it was predicted that coping and appraisals would not make any significant additional contribution to the variance in distress to that accounted for by carers cognitive representation of their relative's psychosis.

Method

Participants

A total of forty-two carers of patients with a diagnosis of schizophrenia, who were attending relative's information and support groups in Worcestershire, were recruited to the study. Participants all had a relative with a formal diagnosis of schizophrenia. Participants were provided with both written and verbal information about the study and all participants provided written informed consent. Participants completed the following questionnaires:

Measures

Representations of Psychosis – The Illness Perception Questionnaire - Revised

The Illness Perception Questionnaire-Revised - IPQ-R; (Moss-Morris, Weinman, Petrie, Horne, Cameron, & Buick *in press)* provided a measure of participants' beliefs about their relative's psychosis. The revised version was developed to improve the psychometric properties of some of the existing scales within the IPQ and to introduce important components of participant's implicit model of illness.

The IPQ-R consists of 7 sub-scales (38 items) which, in this study, included views

about how long carers believed their relative's psychosis would last (timeline), items assessing the relapsing-remitting nature of the condition (timeline cyclical), perceived consequences of the condition, personal control, treatment control, illness coherence, and emotional representations of illness. An adjusted mean score (sum of the scale items divided by the number of items) was calculated, with a possible maximum of 5 for each sub-scale. As the identity subscale for the IPQ-R consists of symptoms that have little relevance to the study of psychosis, the initial symptom frequency count from the 49 item family questionnaire was used (Barrowclough & Parle, 1997; Barrowclough et al, 2001). Thus, participants were asked to rate whether each of 49 symptom behaviours occurred (yielding a scale of 0-49). Potential causes of the condition were assessed by 18 items, scored on a five-point scale from '1' (strongly disagree) to '5' (strongly agree).

Primary and secondary appraisals - Family Questionnaire

The Family Questionnaire (Barrowclough and Parle, 1997) was used to assess primary and secondary appraisals. Participants were asked to rate their degree of concern for problem behaviours identified by them from a list of 49 items, and their confidence in coping with each problem. Following Barrowclough and Parle (1997), individual item responses were collapsed into a two point dichotomised rating used for the measures of the two appraisal variables: threat appraisal 'how much does this problem bother you'; and control appraisal 'how well do you feel able to cope with and control this behaviour'. The number of problems for which a relative gave a positive response were summed (number of problems bothering relative considerably, number of problems for which they had poor control/coping) and these scores were used as threat appraisal

and control appraisal variables respectively.

Coping strategies - Brief COPE

The Brief COPE (Carver, 1997) is a 28 item shortened version of the scale developed by Carver, Scheier, and Weintraub (1989). This measure incorporates 14 distinct scales of 2 items each. The scale requires respondents to indicate the extent to which they use the individual coping strategies to cope with a named event - in this case their relative's psychosis. Scores range from '1' - I usually don't do this at all; to '4' - I usually do this a lot.

Distress – Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983), a 14 item measure, was used to assess distress. Items are rated on a 0-3 point scale indicating the strength of agreement with each item. Thus scores for each subscale ranged from 0 - 21. It has been widely used in studies with patients with psychosis (e.g., Tyrer, Evans, Gandi, Lamont, Harrison-Read, Johnson, 1998) and their relatives (e.g., Oldridge & Hughes, 1992). According to Zigmond & Snaith (1983) a score of >11 on either subscale is suggestive of probable clinical disorder.

Results

Participants were aged between 42 and 70 years (mean =57.3; SD=8.2). Ninety three percent (n=39) of the sample were parents and 7% (n= 3) were spouses or partners.

Duration of their relative's illness ranged from 2 to 14 years (mean = 6.1, SD=3.2). Number of episodes experienced ranged from a single episode to 9 (mean=3.6, SD=2), and age at onset of first episode ranged from 18 to 35 years (mean=24.3, SD=4.1). Sixty four percent (n=27) of the sample was female. Using the cut-off score for probable clinical disorder on the HADS subscales (score >11), 54% (n=23) of participants scored within the range for probable clinical disorder for anxiety, and 38% (n=16) for depression.

In order to utilise the causes dimension of the IPQ-R in further analyses, factor analysis was employed as a means to provide internally consistent causal scales.

Factor analysis of IPQ-R Causes subscale

The causes subscale of the IPQ-R consists of items that are generally assumed to be independent in the nature of causal attributions assessed and are, therefore, not summed to provide an overall scale score. While the number of subjects to items does not permit a check of the stability of the solution in the current study, it was decided to conduct a factor analysis of the scale for exploratory purposes. Thus, principal component analysis with Varimax rotation was employed in the current study.

The first component accounted for 25% of the total variance in the data, and there were three further components with eigenvalues >1. However, Kaiser's criterion (the eigenvalue-one rule) can overestimate the number of components because of sampling effects (Cliff, 1988; Zwick & Velicer, 1984). To compensate for the possibility of sampling error, a scree test (Cattell, 1965), was undertaken which suggested that three

factors should be extracted. This position was confirmed by a reliability analysis. Reliability analysis also indicated that items 4 (diet or eating habits), 5 (chance or bad luck), 6 (poor medical care), 7 (pollution), 10 (family problems), and 18 (altered immunity) could be deleted without affecting the reliability of the scales. The final three factor solution accounted for 68.9% of the variance. The extracted factor solution was subjected to orthogonal rotation using the Varimax method and the final solution is shown in table 1.

Table 1. Varimax three factor pattern matrix for IPQ-R Causes Subscale

	Item	Factor 1	Factor 2	Factor 3
	Biological Attributions.			
3	Germ or virus	**.93**	.27	.21
13	Age	**.85**	.13	.25
2	Hereditary	**.75**	.07	.18
1	Stress or worry	**-.70**	.34	-.28
16	Accident or Injury	**.54**	-.23	-.19
	27.4 % variance.			
	Internal Attributions.			
17.	Personality	-.07	**.86**	-.04
12.	Emotional State	-.25	**.76**	-.09
9.	Mental attitude	.14	**.72**	-.37
8.	Own behaviour	.25	**.66**	.25
	23.3 % variance			
	Behavioural Responsibility			
14.	Alcohol/drugs	.39	-.12	**.82**
15.	Smoking	.08	-.10	**.78**
11.	Overwork	-.11	.32	**.74**
	18.2 % variance			

The first factor showed loadings greater than 0.5 on five items. Items 3 (Germ or virus), 13 (age) and 2 (hereditary factors) best defined this factor. Broadly speaking the six

items concerned biological attributions for cause of psychosis (Cronbach's α =0.8).

The second factor showed loadings greater than 0.5 on four items. This factor was principally defined by items 17 (personality), 12 (emotional state), and 9 (mental attitude). These four items (Cronbach's α =0.74) deal with attributions for cause of psychosis to aspects of the person (internal attributions).

The third factor showed loadings greater than 0.5 on three items (α =0.67). This factor was defined by items 14 (alcohol/drugs), 15, (smoking), 11 (overwork). This factor appears to deal with attributions of behavioural responsibility. Of the illness perception components, alphas for behavioural responsibility for causes, time-line, consequences, and treatment control were fairly low (.65 -.67, see table 2) but fall within acceptable limits.

Reliability of COPE scales

Examination of the internal consistency of the COPE scales showed that a total of 8 coping subscales had questionable construct validity (Cronbach's α's <0.56). Thus, the following coping scales were excluded from subsequent analyses: Acceptance, Active coping, Denial, Humour, Instrumental Support, Planning, Self-distraction and Venting. Cronbach's alpha and mean scores for the measures used in the study are presented in table 2.

Table 2. Mean scores and Cronbach's α reliabilities for Illness Perception Questionnaire (IPQ-R), Family Questionnaire, COPE scales and Hospital Anxiety and Depression Scale (HADS).

	Mean	S.D	α
ILLNESS PERCEPTIONS			
Time line	3.55	.51	.65
Time line cyclical	3.07	.59	.71
Consequences	4.60	.32	.68
Personal Control	3.61	.66	.86
Emotional Representations	3.72	.61	.82
Treatment Control	3.28	.45	.66
Illness coherence	3.03	.74	.89
Illness Identity (symptoms)	14.30	8.1	.93
COPING STRATEGIES			
Substance use	3.02	1.31	.72
Emotional Support	5.00	1.65	.83
Behavioural disengagement	3.54	1.85	.89
Positive Reframing	4.26	1.82	.74
Religion/spiritual beliefs	4.47	2.15	.85
Self blame	4.76	2.09	.95
APPRAISALS			
Primary Appraisals	25.54	9.09	.91
Secondary Appraisals	39.41	8.35	.88
DISTRESS			
Anxiety	11.24	4.80	.90
Depression	8.50	4.11	.86

Gender Differences

There were sex differences on two variables only. Women scored higher than men on emotional representations (*t=3.45, p=0.001)* and on coping through self blame (*t=2.90, p=0.01)*.

In order to identify variables for inclusion into the multiple regression analyses and to control for the possibility of collinearity among the independent variables, simple correlations were computed (table 3). Given the number of correlations undertaken, $p<0.01$ was used as the significance criterion to control for the possibility of Type I error.

Relationships among psychosis perceptions

A stronger illness identity (symptoms) was associated with carer's holding stronger beliefs in chronicity of psychosis (time-line), in the severity of its consequences for their relative, having stronger beliefs in their relative's emotional representations, and weaker beliefs in treatment control and illness coherence. Stronger beliefs about the chronicity of psychosis (timeline) were associated with stronger beliefs in perceived severity of consequences, and weaker beliefs in personal control and treatment control. Stronger beliefs in a cyclical course of psychosis were associated with stronger attributions about behavioural responsibility for causes of psychosis. Stronger beliefs in personal control were associated with weaker beliefs in psychosis lasting a long time and were inversley associated with treatment control. Carers who held stronger beliefs that cause was due to factors associated with the person (internal attributions) also had stronger beliefs that their relative could control their illness and that medical treatments could help in its management.

Relationships among coping strategies

Use of emotional support was associated with positive re-framing and use of religion/spiritual beliefs as forms of coping, and was inversely related to behavioural disengagement. The more behavioural disengagement was used as a strategy by participants, the less positive re-framing was used. Positive re-framing was also associated with greater use of religion/spirituality.

Relationships between illness perceptions, coping and appraisals

Illness identity was associated with greater use of coping through seeking emotional support, less use of positive re-framing, and with greater threat appraisals. Stronger emotional representations were associated with greater use of coping through seeking emotional support, and less behavioural disengagement. Perceptions of more serious consequences were associated with stronger threat appraisals. Stronger beliefs about chronicity of psychosis were associated with less self-reported coping through religion/spirituality. Stronger beliefs in biological causes of their relative's psychosis and stronger attributions that the cause of psychosis was due to factors residing within the patient (internal attributions) were associated with weaker secondary (control) appraisals. Carers who held stronger perceptions that patients could exercise personal control over their condition also held stronger secondary appraisals. Finally, the more episodes carers had experienced the less confidence they had in their ability to cope efficaciously with the demands of their relative's psychosis (secondary appraisals).

Table 3. Pearson's correlations between distress, psychosis representations, clinical history, appraisals, and coping strategies.

	1	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*	*11*	*12*	*13*	*14*	*15*	*16*	*17*	*18*	*19*	*20*	*21*	*22*	*23*
1. Distress																							
2. Identity (symptoms)	**.53****																						
3. Time-Line	**.37***	**.36***																					
4. Time-Line Cyclical	.26	-.09	.03																				
5. Consequences	**.38***	**.57****	**.46****	.07																			
6. Personal Control	**.36***	-.07	**-.38***	-.14	-.01																		
7. Emotional Representations	.03	**.38***	.09	-.22	.26	-.06																	
8. Treatment Control	**-.41****	**-.38***	**-.51****	.12	-.24	**-.61****	-.18																
9. Illness Coherence	-.21	**-.43****	-.11	-.19	-.23	.27	-.24	.29															
10. Biological Causal Attributions	.12	.05	.11	-.04	.11	-.06	.04	-.27	-.11														
11. Internal Causal Attributions	.10	.17	-.29	-.10	.08	**.37***	-.06	**.38***	.01	.00													
12. Behavioural Responsibility	.12	.23	.25	**.37***	.13	-.03	.21	-.16	-.09	.00	.00												
13. Age of carer	**-.41****	-.08	-.25	.12	-.24	.01	-.10	.26	-.13	**-.38***	.15	-.28											
14. Duration	-.17	-.18	-.05	.28	.13	.15	.04	.28	.21	-.04	-.15	.10	-.08										
15. Age at Onset	**-.39***	-.04	-.24	-.20	**-.38***	-.06	-.03	.12	-.08	-.18	.12	-.16	**.64****	**-.45****									
16. Number of Episodes	-.16	.01	-.14	.02	.25	.21	.17	.25	.09	-.08	-.05	.04	-.19	**.54****	-.28								
17. Primary Appraisals	**.56****	**.68****	.29	.05	**.36***	-.09	.22	-.30	-.20	.29	.05	**.42****	-.11	-.15	-.09	-.15							
18. Secondary Appraisals	**-.49****	.08	-.12	.01	.17	**.38***	.02	.24	.13	**-.38***	**-.36***	-.05	.11	.27	.09	**.38***	-.21						
19. Substance Use	.32	-.05	-.06	-.07	-.11	-.21	-.03	-.26	-.05	**.49****	**.39***	.18	-.26	-.17	-.08	-.25	-.07	-.29					
20. Emotional Support	-.26	**.38***	-.04	-.14	-.22	.23	**.38***	.17	-.13	-.28	-.12	-.04	.19	-.13	.23	.07	-.18	**.36***	-.14				
21. Behavioural Disengagement	.26	-.16	-.02	.27	-.09	.04	**-.65****	-.08	-.01	.17	.27	-.07	-.06	-.12	-.01	-.28	-.15	-.33	**.43****	**-.49****			
22. +VE Reframing	**-.52****	**-.36***	-.03	-.09	-.19	.14	.16	-.04	.15	-.19	.05	-.16	.31	-.02	.26	-.03	-.18	**.37***	-.04	**-.36***	-.28		
23. Religion/Spiritual	**-.44****	-.22	**-.39****	-.17	**-.36***	.27	.32	.15	-.22	-.25	-.07	.19	.06	.13	.03	.17	-.32	.17	.02	**.51****	-.25	**.44****	
24. Self-blame	**.41****	.28	.32	-.07	.15	-.22	.26	-.20	.06	-.30	.30	.14	.06	-.12	.05	-.06	.18	-.24	.24	.17	-.18	.31	.02

** Correlation is significant at the 0.001 level (2-tailed). * Correlation is significant at the 0.01 level (2-tailed).

Univariate Associations between Psychological Distress, Illness Perceptions, Coping and Appraisals.

Because the correlation between the anxiety and depression subscales on the HADS was very high (r= 0.83), it was decided to sum the subscales for reasons of parsimony, thus creating a general 'psychological distress' variable. The total HADS score has been used previously in preference to subscale scores due to concerns about the bidimensionality of the scale (Razavi, Delvaux & Farvacques, 1990). Cronbach's alpha for this 'psychological distress' variable was 0.93. The multiple regression analysis was therefore conducted using this combined measure of psychological distress as the dependent variable.

Multiple regression analyses

To examine the influence of illness perceptions, appraisals and coping on psychological distress, a series of hierarchical multiple regression analyses were conducted. Variables which correlated with distress at $p<0.01$(table 3) were entered into the model. Age, and patient's age at onset of psychosis were entered on the first step, retained illness perceptions entered on the second step, primary appraisals on the third step, retained coping strategies on the fourth step and secondary appraisals on the fifth step. Table 4 shows the results of this regression analysis.

Table 4. Regression analysis to determine variance accounted for in self reported distress by clinical/demographic variables illness perceptions, coping, and appraisals

	β	Adj R^2	R^2 Change	F Change	Sig.
1. Demographics		.18	.22	5.30	0.009
Age	-.21				
Age at onset	-.13				
2. Illness Perceptions		.37	.26	3.24	0.02
Timeline,	.11				
Consequences,	.13				
Personal control	**.28**				
Treatment Control	**-.38**				
Illness Identity	.14				
3. Primary Appraisals	.17	.43	.06	4.30	0.04
4. Coping		.74	.27	13.82	0.001
Self blame	**.51**				
Religion/Spirituality	-.22				
Positive Reframing	**-.44**				
5. Secondary Appraisals	-.03	.74	.04	.57	0.45

Using the procedure suggested by Baron and Kenny (1986) to establish coping as a mediator, initial separate regression analysis were undertaken such that firstly, illness perceptions must be shown to affect coping (R^2 = .24); secondly, illness perceptions must be shown to affect psychological distress (R^2 =.42); and thirdly, coping must affect psychological distress (R^2 =.46). Moreover, the effect of illness perceptions alone on distress must be lower than the effects of illness perceptions when entered together with coping (Table 4). The results of the initial regressions and the data presented in table 4 supports coping as a mediator between illness perceptions and distress. Thus the addition of psychosis representations accounted for an additional 26% of the variance in distress scores. Primary appraisals accounted for 6% of the variance when entered after illness perceptions, while coping strategies accounted for a further 27% of the variance in distress scores after demographics, illness perceptions and primary appraisals are co-varied out. Secondary appraisals failed to account for any significant

additional variance. This finding supports a mediational role for coping strategies (chiefly positive reframing and self blame), but the role of appraisals in the model is less distinct. Therefore, this study provides partial support for the self-regulation approach as a means of conceptualising distress in the relatives of patients with a diagnosis of schizophrenia.

Discussion

This is the first study to date that has applied the self-regulation model to distress in carers of people with schizophrenia. The principal aim of the study was to examine whether coping and appraisals were important in accounting for variance in psychological distress or whether psychosis perceptions were adequate on their own. The results demonstrate that aspects of psychosis representations and coping responses play an important role in the extent of distress reported by carers of patients with schizophrenia, while appraisals appear to be much less important in accounting for variance in distress. When coping was entered after both the illness perception components and primary appraisals, coping strategies were still accounting for significant additional variance. This provides some support for the self-regulation model. However the failure of secondary appraisals to account for any significant additional variance suggests that, in the current context, the addition of secondary appraisals to the self regulation model does not provide any further explanatory value to that provided by illness perceptions and coping. Examination of the standardized regression coefficients suggest the importance of two coping strategies as mediators of distress in the self-regulation model: positive re-framing and self blame.

Of the illness perception measures, only those subscales dealing with personal and treatment control showed significant β weights, while the coping subscales of positive re-framing and self blame were the only significant measures of coping that showed significant associations with carer distress in the final regression analyses. Interestingly, carers who held a stronger belief that their relative could exert personal control over their psychosis tended to report more distress, while stronger beliefs in treatment control was associated with less self-reported carer distress. From a methodological standpoint this result supports Moss Morris et al's (2002), decision to develop the cure and control subscale of the original IPQ and treat them as two independent measures in the IPQ-R. The relationship between beliefs in the patient's personal control over their condition and raised carer distress may be a function of views about the patient's role in recovery and expectations about the patient's conduct (Lefley, 1997). Previous studies have assigned a clear role for causal attributions in conceptualisations of outcome in psychosis (Brewin, 1994; Weisman, Nuechterlein, Goldstein & Snyder, 2000; Hooley et al, 1987). While the relation between causal attributions and carer distress were negligible, initial correlations showed a strong relationship between beliefs about causes being due to factors associated with the person and carers assigning responsibility to the patient for them getting better. Indeed, previous research has demonstrated the importance of responsibility appraisals as a marker of the relationship between patient and carer (Provencher & Fincham 2000). In the current context, it may be more likely that proximal responsibility attributions (beliefs that the individual has personal control over the course and outcome of their condition – thus *responsibility for getting better*) would have a greater impact on distress rather

than distal attributions of responsibility (beliefs that the condition is due to factors associated with the individual –thus *responsibility for causes* of psychosis). According to Schlenker and colleagues' triangle model of responsibility, (Schlenker, Britt, Pennington, Murphy & Doherty, 1994), "People are held responsible to the extent that: (a) a clear, well defined set of prescriptions is applicable to an event (prescription-event link), (b) the actor is perceived to be bound by the prescriptions by virtue of his or her identity (prescription identity); and (c) the actor is connected to the event by appearing to have personal control over it (identity-event)" (p.640).

The mediational effect of coping demonstrated in this study is in contrast to a number of studies that have examined the self-regulation model primarily in patients with physical disorders. The majority of these studies have shown that coping does not tend to account for significant additional variance in distress or disability in patients; commonly accounting for substantially less of the variance than illness perceptions (e.g.,Heijmans, 1999; Moss Morris et al, 1996; Steed, Newman & Hardman, 1999). Of course the self-regulation model may provide a better fit in relation to different criterion measures, such as distress, disability, or fatigue. There may also be something quite different about the manner in which coping maps onto cognitive representations of illness in carers and patients respectively. It is interesting to note that the only other study to use the IPQ in carers of people with psychosis (Barrowclough et al, 2001) found that distress correlated only with illness identity and severity of consequences. We also found an association with these measures in our initial correlation matrix (see table3). However, this association failed to hold in the final regression analyses, when the full model was fitted to the data.

It would appear that while primary appraisals of symptoms were associated with distress, carer's appraisals that they could control and cope with their relatives behaviour was not associated with distress as might be expected. Participants who reported greater use of coping by positive re-framing reported less distress, while carers who coped through blaming themselves, unsurprisingly, demonstrated higher distress scores. The strong inverse association between positive re-framing and distress is an important finding that appears to go beyond simple secondary appraisal of symptoms and perhaps into construing benefits from adversity as a function of the care-giver role (Affleck & Tennen, 1996; Veltman, Cameron & Stewart, 2002).

There are a number of potential reasons for the limited contribution made by appraisals to the model. Firstly, appraisals in the current study were limited to appraisals of symptoms, and not with other aspects of the condition. Whilst dealing with symptoms is a major focus of the care-giving role in psychosis (Smith et al, 1993), other issues may also be pertinent to distress in relatives, such as appraisals of stigma (Wahl & Harman, 1989) or of loss and the need to make sense of motivational, interpersonal, social and medical obstacles (Smith & Birchwood, 1990). Secondly, primary appraisals had a mean of 14 points less than secondary appraisals, suggesting a dominance of control appraisals over threat appraisals, with the implication that carers were appraising their ability to cope with the demands placed upon them by their relatives symptoms. However, the inverse relationship between the number of episodes experienced and secondary appraisals is difficult to reconcile with such an explanation. Thirdly there is the possibility of conceptual overlap between primary and secondary

appraisals and distress and coping respectively, although the size of the correlations (table 3) suggests that shared variance was not greater than about 30%.

Some limitations of the study are evident. The small sample size of this study meant that the stability of the three factor solution for the Causes subscale of the IPQ-R could not be assessed. Similarly, the ratio of participants to variables for the regression analysis, while acceptable, is at the lower bound of that recommended (Tatsuoka, 1969). Secondly, the restriction of the sample to people who were attending relatives information and support groups will have implications for the generalisability of results to the general carer population.

Despite these caveats, this study has provided some further support for the utility of the self-regulation approach in relatives of patients diagnosed with schizophrenia. The implications of this study are four fold. Firstly, factors which may protect against distress in relatives of people diagnosed with schizophrenia, include coping through positive re-framing of experience and confidence in current or future effectiveness of treatments for psychosis. Whilst risk factors appear to concern stronger beliefs that the individual is responsible for controlling the vagaries of their condition and an approach to coping characterised by self blame. Secondly, distress seems to have less to do with issues around how well carers feel able to control and cope with symptoms per se. This is supported by the finding that illness identity (perception of symptoms associated with their relative's diagnosis) failed to reach significance in the final regression analyses. It would, therefore, appear that wider issues that may be related to issues of stigma or loss, may be of more importance to the experience of distress in carers of people with

schizophrenia. Thirdly, the stress of care has effects for both younger and more experienced carers in that younger age of the carer was correlated with distress, while number of episodes was associated with poorer appraisals by carers that their resources could meet the demands of their relatives condition. Finally in the light of the recommendations of statutory frameworks (Department of Health, 1999), findings may invite us to consider the use of the self-regulation model as a framework to support carers. Further research is clearly needed on the nature of appraisals of psychosis that are not restricted to symptom dimensions. Similarly, longitudinal research into the stability of illness perceptions over time and their effects on concrete outcomes such as relapse rates and adherence to treatment would be fruitful avenues for further exploration of the self regulation model.

In summary this study has demonstrated that distress in the relatives of patients with schizophrenia is associated with carers holding weaker beliefs in the effectiveness of medical treatment, stronger beliefs that their relative can exert personal control over the symptoms of their condition, and an approach to coping with their relatives condition that is characterised by self-blame and less use of positive re-framing. The results support a mediational role for coping strategies, but the role of appraisals in the model was less distinct. Therefore, this study provides partial support for the self-regulation approach as a means of conceptualising distress in the relatives of patients with a diagnosis of schizophrenia.

References

Affleck, G. & Tennen, H. (1996). Construing benefits from adversity: Adaptational significance and dispositional underpinnings. *Journal of Personality,* **64:** 899-922.

Baron, R.M. & Kenny, D.A. (1986). The moderator-mediator variable distinction in social psychological research: conceptual, strategic and statistical considerations. *Journal of Personality and Social Psychology,* **51:** 1173-1182.

Baronet, A. (1999). Factors associated with caregiver burden in mental illness: a critical review of the research literature. *Clinical Psychology Review,* **19:** 819-841.

Barrowclough, C., Lobban, F., Hatton, C. & Quinn, J. (2001). An investigation of models of illness in carers of schizophrenia patients using the Illness Perception Questionnaire. *British Journal of Clinical Psychology,* **40:** 371-385.

Barrowclough, C. & Parle, M. (1997). Appraisal, psychological adjustment and expressed emotion in relatives of patients suffering from schizophrenia. *British Journal of Psychiatry,* **171:** 26-30.

Barrowclough, C., Tarrier, N. & Johnston, M. (1996). Distress, expressed emotion, and attributions in relatives of schizophrenia patients. *Schizophrenia Bulletin.* **22**:691-702

Brewin, C.R. (1994). Changes in attribution and expressed emotion among the relatives of patients with schizophrenia. *Psychological Medicine,* **24:** 905-911.

Carver, C.S., Scheier, M.F. & Weintraub, J.K. (1989). Assessing coping strategies: a theoretically based approach. *Journal of Personality and Social Psychology.* **56;** 267-283.

Carver, C.S. (1997). You want to measure coping but your protocol's too long: consider the Brief COPE. *International Journal of Behavioural Medicine,* **4**: 92-100.

Cattell, R.B. (1965). Factor analysis and introduction to essentials: (1) The purpose and underlying models. *Biometrics,* **21:** 190-215.

Cliff, N. (1988). The eigenvalues-greater-than-one rule and the reliability of components. *Psychological Bulletin,* **103:** 276-279.

Cuijpers, P. (1999). The effects of family intervention on relatives burden: a meta analysis. *Journal of Mental Health,* **8:** 275-285.

Department of Health (1999). *A National Service Framework for Mental Health.* London. DoH publications.

Fadden, G. (1998). Family intervention in psychosis. *Journal of Mental Health,* **7:** 115-122.

Fadden, G., Bebbington, P. & Kuipers, E. (1987). The burden of care: The impact of functional psychiatric illness on the patient's family. *British Journal of Psychiatry,* **150:** 285-297.

Heijmans, M. (1999). The role of patients' illness representations in coping and functioning with Addisons disease. *British Journal of Health Psychology,* **4:** 137-149.

Hooley, J.M., Richters, J.E., Weintraub, S. & Neale, J.M. (1987). Psychopathology and marital distress: The positive side of positive symptoms. *Journal of Abnormal Psychology,* **96:** 27-33.

Lefley, H.P. (1997). The consumer-recovery vision: Will it alleviate family burden. *American Journal of Orthopsychiatry,* **67:** 210-219.

Leventhal, H., Benyamini, Y., Brownlee, S., Diefenbach, M., Leventhal, E., Patrick-Miller, L. & Robitaille, C. (1997). Illness representations: Theoretical foundations. In K. Petrie & J. Weinman (Eds). *Perceptions of Health and Illness* (pp19-46). Amsterdam. Harwood Academic Publishers.

Leventhal, H., Meyer, D. & Nerenz, D. (1980). The common-sense representation of illness danger. In S. Rachman (ed) *Contributions to Medical Psychology* (Vol 2, pp. 7-30). New York: Pergamon Press.

Leventhal, H., Diefenbach, M. & Leventhal E. (1992). Illness cognition: Using common-sense to understand treatment adherence and affect-cognition interactions. *Cognitive Therapy and Research,* **16:** 143-163.

Magliano, L., Fadden, G., Fiorillo, A., Malangone, C., Solrrentino, D., Robinson, A. & Maj, M. (1999). Family burden and coping strategies in schizophrenia: are key relatives really different to other relatives. *Acta Psychiatrica Scandinavica,* **99:** 10-15.

Moss-Morris, R., Weinman, J., Petrie, K.J., Horne, R., Cameron, L.D. & Buick, D. (2002). The revised Illness Perception Questionnaire (IPQ-R). *Psychology and Health,* **17:** 1-16.

Moss-Morris, R., Petrie, K. & Weinman, J. (1996): Functioning in chronic fatigue syndrome: do illness perceptions play a regulatory role? *British Journal of Health Psychology,* **1:** 15-25.

Oldridge, M.L & Hughes, I.C.T (1992). Psychological well-being in families with a member suffering from schizophrenia: An investigation into long-standing problems. *British Journal of Psychiatry,* **161:** 249-251.

Petrie K.J. & Weinman, J.A. (1997). *Perceptions of Health and Illness.* Amsterdam. Harwood Academic Publishers.

Provencher, H. & Fincham, F. (2000). Attributions of causality, responsibility and blame for positive and negative symptom behaviours in caregivers of persons with schizophrenia. *Psychological Medicine,* **30:** 899-910.

Provencher, H.L., Fournier, J.P., Perreault, M., Vezina, J. (2000). The caregiver's perception of behavioral disturbance in relatives with schizophrenia: a stress-coping approach. *Community Mental Health Journal,* **36**:293-306.

Razavi, D., Delvaux, N. & Farvacques, C. (1990). Screening for adjustment disorders and major depressive disorders in cancer in-patients. *British Journal of Psychiatry*, **156**: 79-83.

Scharloo, M., Kaptein, A.A., Weinman, J., Hazes, J.M., Willems, L.N.A., Bergman, W. & Roojimans H.G.M. (1998). Illness perceptions, coping and functioning in patients with rheumatoid arthritis, chronic obstructive pulmonary disease and psoriasis. *Journal of Psychosomatic Research,* **44:** 573-585.

Schene, A.H., van Wijngaarden, B. & Koeter, M.W.J. (1998). Family caregiving in schizophrenia: domains and distress. *Schizophrenia Bulletin,* **24:** 609-618.

Schlenker, B.R., Britt, T.W., Pennington, J., Murphy, R. & Doherty, K. (1994). The triangle model of responsibility. *Psychological Review,* **101:** 632-652.

Smith, J.V. & Birchwood, M.J. (1987). Specific and non-specific effects of educational intervention with families living with a schizophrenic relative. *British Journal of Psychiatry,* **150:** 645-652.

Smith, J.V., Birchwood, M. & Cochrane, R. (1993). The needs of high and low expressed emotion families. *Social Psychiatry and Psychiatric Epidemiology,* **28:** 11-16.

Smith J.V. & Birchwood, M. (1990). Relatives and patients as partners in the management of schizophrenia: Development of a service model. *British Journal of Psychiatry,* **156:** 654-662

Solomon, P. & Draine, J. (1995). Subjective burden among family members of mentally ill adults: relation to stress, coping, and adaptation. *American Journal of Orthopsychiatry,* **65:** 419-27.

Steed, L., Newman, S.P., Hardman, S.M.C. (1999). An examination of the self-regulation model in atrial fibrillation. *British Journal of Health Psychology,* **4;** 337-347.

Tatsuoka, M.M. (1969).Selected Topics in Advanced Statistics: An Elementary Approach. Number 5. *The Use of Multiple Regression Equations.* Illinois. The Institute for Personality and Ability Testing.

Tennakoon, L., Fannon, D., Doku, V., O'Ceallaigh, S., Soni, W., Santamaria, M., Kuipers, E., Sharma, T. (2000). Experience of caregiving: relatives of people experiencing a first episode of psychosis. *British Journal of Psychiatry,* **177:** 529-33

Tyrer, P., Evans, K., Gandi, N., Lamont, A., Harrison-Read, P. & Johnson, T. (1998). Randomised controlled trial of two models of care for discharged psychiatric patients. *British Medical Journal,* **316:** 106-109.

Veltman, A., Cameron, J.I. & Stewart, D.E. (2002). The experience of providing care to relatives with chronic mental illness. *Journal of Nervous and Mental Disease,* **190:** 108-114.

Wahl, O.F. & Harman, C.R. (1989). Family views of stigma. *Schizophrenia Bulletin.* **15:** 131-139

Webb, C., Pfeiffer, M., Meuser, K.T., Gladis, M., Mensch, E., DeGirolamo, J. & Levinson, D.F. (1998). Burden and well-being of caregivers for the severely mentally ill: the role of coping style and social support. *Schizophrenia Research,* **34:** 169-180.

Weisman, A.G., Nuechterlein, K.H., Goldstein, M.J. & Snyder, K.S. (1998). Expressed emotion, attributions, and schizophrenia symptom dimensions. *Journal of Abnormal Psychology*. **107**:355-359.

Zigmond, A. & Snaith, R. (1983): The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, **67:** 361-370.

Zwick, W.R. & Velicer, W.F. (1986). Comparison of five rules for determining the number of components to retain. *Psychological Reports,* **99:** 432-442.

CHAPTER 4

Research Review

'If That's the Answer, Then What's the Question?' Some Personal Reflections on Developing a Research Protocol from Clinical Practice.

Summary

The purpose of this paper is to provide a methodological overview of a research project on patients' and relatives' perceptions of schizophrenia and its impact. More specifically this paper aims to provide a reflective review of the research process - how the ideas for the research came about and where they arrived at. It also aims to highlight the choice and use of methods in attempting to answer some of the research questions. This paper will further attempt to explicate the clinical and epistemological implications of setting up, conducting and disseminating the research. Thus, a core feature of this paper concerns my own personal reflections of conducting pragmatic clinical research.

Introduction

This paper broadly concerns methodology and the role that methodology occupies in relation to the development of a research project on patients with a diagnosis of schizophrenia and their key relatives. This paper tells the story of this research and begins with decisions about points of departure, to a means of travel and 'technologies' for navigating the route. It is concerned with reflections on conducting pragmatic clinical research. However this paper is also about the relationship between the often dichotomised clinical and research identities of the applied psychologist working in clinical settings and its implication for the process and outcomes of research.

A Point of Departure

> *"Where do I go from here", asked Alice?*
> *"That depends on where you want to get to", said the Cat.* (Lewis Carroll).

About two years ago, I was a psychologist in clinical training on a core adult mental health placement. Part of this clinical placement involved co-facilitating psycho-education and support groups for people who had received a diagnosis of schizophrenia or bi-polar disorder. In one of the early sessions, Tony, who was recovering from his first episode of schizophrenia, was discussing a particular difficulty that he was currently experiencing. He was able to describe this difficulty as a sense of feeling trapped and stigmatized within his own family. He went on to relate that this sense of feeling trapped revolved, paradoxically, around his current feelings of confidence about 'getting back into life' and that his

psychotic episode need not mean that he would continue to have additional episodes. On the other hand he heard his family, expressing obvious concern and love for him, stating that he should try to get a less demanding job now, that perhaps he should stay home more often, and that it was not the best idea to go back to his workplace where people knew he had 'these problems'. They asked what if something happened and they couldn't access services immediately to control his condition, they checked whether his desire to 'get back into life' was an early sign of an impending episode. They particularly feared the consequences for him should a further episode occur and continued to counsel him not to tell people that he had been under psychiatric care. Tony's concerns were echoed by quite a few other members of the group and it seemed that one of the key themes that emerged from their stories, was something around the potential for mismatch between the needs of the person who had been diagnosed and their key relatives. Some group members discussed that it felt like they and their family members had experienced and witnessed psychosis so differently and saw potential dangers, benefits or risks in so many different areas, that it seemed that they had witnessed and experienced completely different illnesses or events. This seemed to be a source of some distress for group members, as they recounted that while they believed that family members had their best interests at heart, their ideas about psychosis – what we might understand as the implicit model held by their relatives - was not necessarily congruent with the person's ideas and understanding of it.

I began reflecting on this mismatch between such models of psychosis, the stigma that attaches itself to a label of schizophrenia, and the possibilities of conducting some research in relation to this. If the products of Tony's story were the answer, then what was the question? I began thinking about linking what I observed clinically to an appropriate theoretical and empirical base.

Using Theory to Map the Route

"You cannot weigh an elephant on a pair of kitchen scales"
(Main, 1987, p.31).

I needed a theory that would allow me to weigh part of the elephant! After much thought and discussion, I eventually arrived at a theory that I felt had potential to adequately account for the story that had been shared in the group. Leventhal's self regulation approach (Leventhal, Meyer & Nerenz, 1980; Leventhal, Benyamini, Brownlee, Diefenbach et al, 1997) seemed to be the most appropriate theory to locate the questions which were brought up by the group session, and thus to inform the research methodology. This approach has received increased attention in recent years as evidence supporting the importance of interpretative processes between objective demands and subjective states has entered the literature as part of a general information processing approach to cognition and behaviour (e.g., Petrie & Weinman, 1997; Barrowclough, Lobban, Hatton & Quinn, 2001).

Self regulation theory is predicated upon peoples' own common-sense beliefs about a particular illness or disorder. According to this model, people are active processors of information about disease and illness and build up quite complex cognitive models or representations of such illnesses or experiences. These representations in the form of illness perceptions guide coping and are said to influence appraisals of 'illness' threat and psychological outcomes. Cognitive representations about a condition are based on generic memorised information about health and illness, information patients will receive from their doctor, and lay information from family and friends and from the wider media. The major attributes of illness representation are oriented around a number of dimensions of the illness experience: perceptions about potential causes of the condition; perceived consequences; beliefs about its cure or control; expected duration or clinical course of the condition; perceptions of 'illness' coherence; emotional representations; and Illness identity, which concerns the symptoms patients experience as part of their condition.

Aspects of the key components of the model were already evident in the family narrative reported by our group member, and showed differences with his own personal model, all of which were yielding particular forms of communication, behaviour and affect within the family. In particular, ideas about illness identity ('this behaviour may be an early symptom or sign of psychosis'), ideas about cause (the suggestion to get a less demanding job carries the implication that stress is a principal aetiological factor), controllability ('we need to be close to

services, medicines are our main agents of control'), Time line ('it is likely to be recurrent'), and consequences (stigmatization – 'you should keep your psychiatric history a secret'). Thus this model seemed to provide a reasonable fit to the clinical data – the experiences of the group members.

I also felt that the approach would yield information that might have important clinical implications for the nature of work with people diagnosed with a psychotic illness.

Indeed, according to Johnson & Orrell (1995):

> *"In clinical practice, a better understanding of the lay pattern of belief about mental illness which may shape a patient's insight, and of any cultural variations in these belief systems, may lead to a better therapeutic relationship with the patient and greater scope for reaching agreement on a treatment plan and for effective psychoeducational work with patients and families"* (Johnson & Orrell, 1995 p. 519).

The decision to conduct research in this area was not taken lightly and was taken with some awareness of the difficulties in conducting research with people diagnosed with a psychotic illness and their relatives. Much of research has tended to view clients descriptions of their experiences as unreliable or invalid, and their lack of insight as absolute and invariable (MacCarthy & Liddle, 1994). However, other studies have shown that while acutely ill patients have difficulty reporting on their experiences, patients in remission or with residual symptoms give accounts which show stability over time and tend to be consistent with

external observations (Barrowclough, Haddock, Lowens, Connor, Pidiswji & Tracey, 2001; Cutting & Dunne, 1989; Barker, Lavender & Morant, 2001). I felt that this research could provide information that might have some clinical utility in assessing clients and in considering whether such methods might prove helpful as a means to evaluate treatment outcomes. I also felt participation might permit clients and their relatives to recognise and make explicit aspects of their common-sense model and assess its goodness of fit for them.

Maps, meanings, and making sense

"To untangle a snarl, loosen all jams or knots....
Keep the snarl open and loose at all times and do not pull on the end; permit it to unfold itself."
(The Ashley book of Knots)

This paper will use quotes from consenting participants who wrote either in response to the requests for participants, or who wrote following their completion of the questionnaires. The presentation of quotes does not attempt to employ a formal analytic technique to the choice and presentation of this data, but is used here simply as a means to illustrate some of the authors reflections on this body of work and to depict avenues for further research. Such quotes are presented here only from those participants who gave consent for their words to be used.

I expected there would be some difficulties with people not wishing to participate (i.e., either the person who has received the diagnosis or their relative), however there was the additional consideration of the intimate dyadic relationship between

participants, which was a significant barrier to recruitment. Some people felt that agreeing to participate - agreeing to tell me their beliefs about their relative's experiences - was akin to a sense of unfaithfulness or betrayal.

> *"I had another look at the information you were kind enough to give me again. I know I said to you that I would help with your studies and I do feel really bad about this but I think if I answered these questions I'd be betraying him. I mean I know he would not think this, but I just do not want to be unfair to him"* (Margaret)

Moreover, some people felt that they had moved on, and research of this type was reminding them of a period of engulfment that they would rather forget, even though they may still have been experiencing residual symptoms.

> *"I hope this clarifies the fact that this for me is reliving the past. I have had more than enough. By the way I am a certificated counselor"* (Peter)

Other people found that participating gave an opportunity to consider their own expertise in relation to psychosis and the manner in which it may be valued somewhat less than it could be.

> *"Despite my wanting to be involved with her care, I still feel shut out, ignored and an interfering parent as if I was the cause of her problems. I feel I have a lot to offer, to put into context without distortion or exaggeration. Much family background has not been taken into account and no one takes any time talking to her, gaining her trust and confidence, therefore what has happened to her remains deep inside her – a secret."* (Carol)

In addition, some participants wrote offering insights into their implicit model of their relative's psychosis or the difficulties they were having in arriving at a personal model that showed coherence for them.

> *"We have been given the help of a psychiatrist and now a CPN which we all like. But we as relatives feel confused now as to which is her illness and which is normal behaviour !"* (John)

Other people had hopes for the future that was fraught with challenges of negotiating between dependence and independence.

> *"I only hope that Bob who will be 45 at the beginning of April can cope on his own and be continued to be monitored because he is man enough not to have me breathing over his shoulder all the time - and he doesn't want it".* (Frances)

In addition to patients' and relatives' experiences in the 'here and now', participants also offered supplemental information suggesting that the 'maps' that people use as a context for meaning can often go back generations. This supports previous research which shows that severe mental illness in families can be remembered for up to 5 generations (Sartorius, 2000). Many participants mentioned ideas about causation often stretching back two or more generations.

> *"The psychosis has come down through the male genes on my late husbands fathers side of the family. My daughter has no problems. I have three sisters with family and there are no psychotic problems."* (Janet)

"Had [grandmother] been honest about her mental problems at the time of her marriage, my life wouldn't have been the living hell that it is now." (Petra)

"I remember my grandad at night smoking out of the top window of the house [believing] that someone was going to come and take him away. Obviously this is a story that has been told to me by someone because I would not have been born. Its like I have a real memory of him in his room like that and when I see Jason just lying around in his room, its like there is some weakness that we always have had and I am afraid we always will have. We need a cure from this - I would not like to think that in a hundred years someone will be telling a story about him..." (Mariette)

Other participants gave unique insights about how they navigated the everyday potential for stigma inherent in a psychiatric diagnosis.

"I never call it schizophrenia or psychosis. I call it depression. If I tell another person about what has happened to me, I call it depression. It's easier like this for everyone." (Kath).

"I now feel that I have enough of my identity back not to have to use this psychotic episode as a label, but I also long to be fully integrated into society again and avoid pointing out what could be a hurdle for another to understand/deal with, before accepting/trusting me." (Elaine)

The words of participants and of those who declined to be interviewed further, demonstrated a number of features, which supported the validity of the methodology chosen and of the attempt to elucidate a personal or implicit model of participants' illness or experiences. However, these narratives also demonstrated a particularly important theme that I had not explicitly included in the research protocol but which permeates every aspect of it - disclosure. In its

relation to stigma, disclosure would be expected to play a crucial role and there is little in the literature that examines the process of disclosure in people with a diagnosis of schizophrenia and their family. This would be a fruitful avenue for future research. The methodology for these kinds of studies would have to recognise that the relationship between the researcher and researched will be likely to have an important bearing on the nature of the results: it would demand a different approach to research that makes such subjectivities explicit. While views about such research are changing, it is probably fair to say that there is still something of a reluctance to accord research of this type the same weight as more quantitative, objective research.

How you travel is more important than when or where you arrive.

> *"A monk told Joshu: "I have just entered the monastery.* Please teach me."
> *Joshu asked: "Have you eaten your rice porridge?"*
> *The monk replied: "I have eaten"*
> *Joshu said: "Then you had better wash your bowl"*
> (Capra, 1975, p.126)

In applied psychology there is still an ideal about conducting research. This ideal is to do with being disinterested and value free. It concerns the notion that researchers occupy a somewhat 'higher plane' focused onto their hypotheses, methodology, and objectivity and are thus not concerned with the everyday 'messiness' of their research participants lives. If one subscribes to this approach there is a dialectical tension here for the clinical researcher. The need to accurately represent participants' views without distortion, while also recognizing that as the interviewer I am a part of this research process and by virtue of this

am likely to have an effect on the responses given by participants. There will be demand characteristics at work, and responses on questionnaires have no absolute monopoly on truth. They are metarepresentations - beliefs people hold about beliefs that they hold. According to Woodward (2000), we all live in storied worlds and the stories we tell about ourselves and others are dependent upon our meta representations of the story as well to whom we are telling the story. This is at variance with the idea of the researcher seeking only answers to important questions and being divorced from everyday life. Keeping a foot in the everyday world of research participants lives, permits some form of reciprocity, recognizes the value and importance of participants responses within this context and that people have invited us in. Obviously this is a privilege but it is also a responsibility. It is a privilege because it allows access to an aspect of their world and permits us to go beyond the hypothesis testing straightjacket. It is a responsibility because we now have an increased ethical accountability to participants, both in terms of accurately representing their views, but also in allowing people a frame or context by which they might choose to deliver this information and receive something back. In this sense we become an integral part of the research process, our standpoints (aspects of ourselves that have the potential for proclivity) are made explicit, our biases transparent, our reasons for conducting this particular research, unambiguous.

In a similar way, people have very different reasons for participating in a research programme. Some people will find it easier to take part because it is a

confirmation of something that has been given an importance and a power that has allowed them to construe 'benefits out of adversity' (Affleck & Tennen, 1996). There is growing recognition that for some people the 'personal is the political' and this confirmation may aid in the empowerment of the individual (Corrigan & Watson, 2002). For others, the personal is pejorative and is a perceived as a significant source of stigma and distress. These participants clearly have a different reason for participating, which may have to do with attempts to arrive at a context for meaning in relation to their story, or it may be to do with addressing psychological needs, and the perception that the researcher functions as a gatekeeper to addressing such needs. These factors are likely to have had an influence on the data and yet I have no way of integrating or addressing this other than to reflect upon it in the current paper.

For me this whole research process is not about an end product that might be acceptable for a peer reviewed journal (although that would be a nice adjunct). I think it is much more about learning about doing clinically relevant research, learning from the challenges that will be presented such as trying to help uninterested staff or potential participants become interested in these questions, and thinking flexibly about possible solutions to such challenges. It is about developing an idea, and refining this idea in the light of challenges that test its internal validity (such as perhaps new information coming to light which will change the aspects of the research focus) or that tests its external validity (does it have a practical clinical application).

Walking with both feet is better than hopping on one
(or the importance of embracing clinical and research positions)

"For 1 week only, Todd Williams, banging nails into the floor with his head".
(sign outside a theatre in Vancouver)

It is easy for research and clinical practice to become divorced from each other. My personal experience of conducting research and indeed of training is that there is something of a false dichotomy at work in clinical psychology. Yet the core skills for research and clinical work are the same. According to Marzillier (1998),

> *"the most important part of any training programme....[is] the capacity to think critically and psychologically about one's own and other peoples' work" (p12).*

By this statement I think Marzillier is not talking simply about reflecting and being reflexive (although the importance of this is certainly implicit in this statement). He is talking more about the marriage of technology and knowledge – the ability to understand and use the knowledge available in the psychological world to work effectively and psychologically with individuals, organisations and systems.

For me the ideal would involve not necessarily hopping from clinical to research to clinical in a pragmatic manner, such that clinical work allows access to questions that can be addressed through research and which can then be fed back into clinical practice. It is more about accessing both limbs simultaneously.

It is about a higher level skill. David Smail writing about the distinguishing features of clinical psychology states:

> *"No-one else but us uses a relevant, critical empirical knowledge base to try to make sense of our clients distress, formulate its causes, measure attempts at change, calculate the possibilities of prevention as well as 'cure' and provide explanations when neither proves possible"* (Smail, 1998; p.22).

Becoming involved in this research has demonstrated to me the concordance rather than the discordance between the clinical and research worlds. It is about thinking psychologically, accepting that we as individuals are intuitive scientists, drawing upon our implicit theories to provide a context for meaning in relation to our concerns, formulating hypotheses on the basis of data and testing them, keeping or discarding elements of our theories or implicit models in the light of new information, and recognising our own place and our own interpretative biases within this.

A kind of arrival

"To a man with a hammer, an awful lot of things look like a nail"
(Anon)

I am convinced that entering into this research armed with theory biased my research in particular directions. It is likely to have biased it not only in interpretation of results – what information is put out into the public domain; but at an earlier stage it will have been biased in relation to the nature of information that was permitted in to the research design. It may be a tautology but in quantitative research one can only get answers to the questions that are asked. Linking one's clinical data to an empirical base is an example of data-driven research and helped to fit a more contextual frame to the research design. The questions were generated from the qualitative forum that is clinical work. Theory anchored the questions and permitted an interpretation in line with this theory. The questions that I asked in response to the answers that came from that initial group over two years ago, were limited in their scope and the methodology that they informed could only provide a limited but a not altogether limiting picture. Nonetheless, they invited me to reflect upon the role of research in clinical psychology, the effects on my participants, and my role as a psychologist in clinical training. This reflective review has allowed me to access a further question of research - 'what is this information for, who does it serve, and for what purpose'?

I am pretty sure that the academic and clinical worlds will not be tremendously stirred by my efforts. I doubt if anything terribly substantive will immediately come from this research that will serve to alleviate the distress of patients or that of their relatives. I would hope that participation in the research gave participants the space or permission to reflect on the continued authorship of their lives, as indeed I will continue to do. Interestingly, I do not feel disheartened about continuing with clinically relevant research. I may just get better at asking better questions and hopefully I will recognise where they came from and where they might lead. In this paper, I have reflected upon issues that I am sure are not novel, but they remain so for me. Once I started thinking about the purpose of this research, I found that others have struggled with these ideas before me and indeed have struggled far more eloquently.

> *"So we see that [scientists] approached nature with intellectual passions and with beliefs inherent in these passions, which led them to their triumphs and misguided them to their errors. These passions and beliefs were theirs, personally, even though they held them in the conviction that they were valid, universally. I believe that they were competent to follow these impulses, even though they risked being misled by them. And again, what I accept of their work today, I accept personally, guided by passions and beliefs similar to theirs, holding in my turn that my impulses are valid, universally, even though I must admit the possibility that they may be mistaken"* (Polanyi, 1958; *p.279).*

References

Affleck, G. & Tennen, H. (1996). Construing benefits from adversity: Adaptational significance and dispositional underpinnings. *Journal of Personality,* **64:** 899-922.

Barker, S., Lavender, T., & Morant, N. (2001). Client and family narratives on schizophrenia. *Journal of Mental Health,* **10**: 199-212

Barrowclough, C., Haddock, G., Lowens, I., Connor, A., Pidiswji, J., & Tracey, N. (2001). Staff expressed emotion and causal attributions for client problems on a low security unit: an exploratory study. *Schizophrenia Bulletin,* **27:** 517-526.

Barrowclough, C., Lobban, F., Hatton, C. & Quinn, J. (2001). An investigation of models of illness in carers of schizophrenia patients using the Illness Perception Questionnaire. *British Journal of Clinical Psychology,* **40:** 371-385.

Capra, F. (1975). *The Tao of Physics.* Suffolk. Fontana.

Cutting, J. & Dunne, F. (1989). The subjective experience of schizophrenia. *Schizophrenia Bulletin,* **15:** 217-231.

Johnson, S. & Orrell, M. (1995). Insight and psychosis: a social perspective. *Psychological Medicine,* 515-520.

Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common-sense representation of illness danger. In S. Rachman (Ed.) *Contributions to Medical Psychology,* (Vol 2, pp. 7-30). New York. Pergamon.

Leventhal, H., Benyamini, Y., Brownlee, S., Diefenbach, M., Leventhal, E.A., Patrick-Miller, L. & Robitaille, C. (1997). Illness representations: theoretical foundations. In K.J. Petrie & J.A. Weinman (Eds.), *Perceptions of Health and Illness,* (pp.19-46). Amsterdam. Harwood Academic Publishers.

MacCarthy B. & Liddle, P. (1994). The assessment of subjective experience and insight. In T.R.E. Barnes & H.E. Nelson (Eds.), *The Assessment of Psychosis* (pp.105-124). London. Chapman and Hall.

Main, C.J. (1987). An irreverent look at the research industry. *Clinical Psychology Forum,* **9:** 27-32.

Marzillier, J. (1998). Identity crises and clinical psychology. *Clinical Psychology Forum,* **120:** 9-13.

Polanyi, M. (1958). *Personal Knowledge.* Chicago. University of Chicago Press.

Sartorius, N. (2000). Paper Presented to the Royal College of Psychiatrists Annual Meeting, Edinburgh, 4 –7th July 2000.

Smail, D. (1998). What's it all about? *Clinical Psychology Forum,* **119:** 22-24.

Williams, D.D.R. & Garner, J. (2002). The case against 'the evidence': a different perspective on evidence-based medicine. *British Journal of Psychiatry,* **180:** 8-12.

Woodward, C. (2000). Hearing voices: research issues when telling respondents' stories of childhood sexual abuse. In C. Truman, D.M Mertens, & B. Humphries (Eds). *Research and Inequality.* (pp.37-51). London. UCL press.

Appendix 1

APPENDIX I

Worcestershire NHS
Health Authority

Isaac Maddox House
Shrub Hill Road
Worcester
WR4 9RW

Tel: 01905 760000
Fax: 01905 26159
DX 709431 Worcester 7

WORCESTERSHIRE
LOCAL RESEARCH ETHICS COMMITTEE

Dr D Fortune
44 Broomfield Road
Southcrest
Redditch
Worcestershire B97 4PN

Our ref: KG/
Your ref:
11 September 2001

Direct Line: (01905) 760091
Fax Line: (01905) 617051

E-mail Number:
Kath.Garrad@wha.worcester-ha.wmids.nhs.uk

Dear Dr Fortune

Re: LREC: 01/34 ***(please use in all correspondence)***

Patients and relatives perceptions of psychosis
(Local Researcher: Dr D Fortune, Dr J Smith, Dr K Garvey, Dr B Campbell, Dr J Kucharska, Dr D Markham)

Papers reviewed:

- **LREC application form received 23rd April 2001**
- **Protocol, received 23rd April 2001**
- **CV for Dr D Fortune**
- **Information Sheet, version 4, dated 24th August 2001**
- **Relative's Consent Form, version 4, dated 24th August 2001**
- **Letter to patient**
- **Recruitment Protocol Flow Chart for participants, version 3, dated 4th August 2001**
- **Letter to Doctor**
- **Letter to relative**
- **CV for Dr K Garvey**
- **Your views about your experiences questionnaire**

THIS APPLICATION HAS BEEN GIVEN A UNIQUE REFERENCE NUMBER. PLEASE QUOTE THIS ON ALL CORRESPONDENCE.

APPENDIX II

Warwickshire NHS
Health Authority

PAH

30 August 2001

Westgate House
Market Street
Warwick CV34 4DE

Tel: 01926 493491
Fax: 01926 495074

WARWICKSHIRE RESEARCH ETHICS COMMITTEE

The following LREC trial protocol has been examined from an ethical viewpoint and the decision of the Committee is as follows:

			Documentation Reviewed *as itemised in ICH guidelines*	
1.	*	Approved	**Protocol**	☑
			Patient Information Form/	☑
			Consent Form	☑
2.		Approved subject to amendments listed below	**Indemnity (signed)**	☑
			CTX	☐
			Protocol Amendments	☐
3.		Rejected for reasons listed below		
4.		Approved by Chairman's Action		

Ethical Committee Minute Number 540/01 Dated 22nd August 2001

Protocol Title and Reference Number
RE 485 Patients and relatives perception of psychosis
(Dr. D. Gerard Fortune)

Signed.....Committee Chairman

Dated...30/8/01.....

This approval is subject to the following standard conditions :

1. the study must begin within one year;
2. the researcher must seek the Committee's approval in advance of any Proposed deviations from the original protocol;
3. any unusual or unexpected results which raise questions about the safety of the study must be reported to the Committee.
4. progress reports must be submitted to the Committee annually; and
5. a summary of the study's findings must be submitted to the Committee upon its Completion.

APPENDIX III

COVENTRY UNIVERSITY – SCHOOL OF HEALTH AND SOCIAL SCIENCES

STUDENT SUBMISSION TO SCHOOL RESEARCH ETHICS COMMITTEE

1. Student's name: DR. DONAL FORTUNE 2. Course: D.CLIN.PSY

3. Title of project: GENERAL PUBLIC PERCEPTIONS OF PSYCHOSIS.

4. Summary of project in jargon-free language and in not more than 120 words

Objective: The objective of the study is to survey general public perceptions of psychosis.

Background: The proposed study is an adjunct to our Warwickshire and Worcestershire LREC approved study 'Patient and relatives views of psychosis'. The proposed study sets out to provide data from a non clinical population for comparative purposes with data from the clinical sample.

Design: This is a cross sectional study. Participants will be asked given information about the study, and will complete a consent form and a questionnaire – the illness perception questionnaire (revised form). Participants will be members of the general public living in Worcestershire. Inclusion criteria: aged 18 to 65, no impediment to completing said questionnaire. Exclusion criterion: member of family with a diagnosis of schizophrenia. A total of 20 participants are required.

Access arrangements (if applicable):

5. Will the project involve patients (clients) and/or patient client) data? Yes [ ] No [✓]

6. Will any invasive procedures be employed in the research? Yes [ ] No [✓]

7. Is there a risk of physical discomfort to those taking part? Yes [ ] No [✓]

8. Is there a risk of psychological distress to those taking part? Yes [ ] No [✓]

9. Will specific individuals or institutions (other than the university) be identifiable through data published or otherwise made available? Yes [ ] No [✓]

10. Is it intended to seek informed consent from each participant (or from his or her parent or guardian)? Yes [✓] No [ ]

Student's signature: Donal Fortune Supervisor's signature: K.A. Gamy Date: 8th Feb, 2002

FOR COMMITTEE USE:

Immediate approval	[✓]	Referral to full School Committee	[ ]
Referral to local Hospital Ethics Committee	[ ]	Decision pending receipt of further information (specify below)	[ ]

Committee Member's signature: David Giles Date: 8/2/02

Appendix IV

PATIENT CONSENT FORM

Title of Project: Patients and Relatives' Views about the Experience of Psychosis
Name of Researcher: Dr. Donal Fortune

Please initial box

1. I confirm that I have read and understand the information sheet dated 24th August 2001 (version 4) for the above study and have had the opportunity to ask questions ☐

2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected ☐

3. I give permission for the researcher to inform my GP that I have agreed to participate in this study ☐

4. I give permission for the researcher to contact my nominated relative for the purposes of this study ☐

5. I agree to take part in the above study ☐

Name of Patient	Date	Signature
Name of person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

Consent form version 4; 24th August 2001

Appendix V

CARER CONSENT FORM

Title of Project: Patients and Relatives' Views about the Experience of Psychosis
Name of Researcher: Dr. Donal Fortune

Please initial box

1. I confirm that I have read and understand the information sheet dated 24th August 2001 (version 4) for the above study and have had the opportunity to ask questions ☐

2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving any reason, without my legal rights being affected ☐

3. I agree to take part in the above study ☐

Name of Participant	Date	Signature
Name of person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

Consent form version 4; 24th August 2001

Appendix VI

An Information Sheet for Study Participants

Patients and Relatives Views About the Experience of Psychosis

You are being invited to take part in a research project. Here is some information to help you decide whether or not to take part. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Ask us if there is anything you do not understand or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this information sheet.

What is the study about?

People who have received a diagnosis of psychosis are likely to hold a wide range of beliefs about their experiences. For example, some people may hold the view that their experiences are due to an illness (which may have been diagnosed as schizophrenia) while other people may hold other views about their experiences. In a similar way, family members would also be likely to have views about the person's experiences. For some people these views may be quite similar to the person who has received the diagnosis, while for others they may be less similar. We are interested in finding out the ways in which you and a member of your family view your experiences and the impact they have on your lives. Information obtained during the course of the study may help us to understand better the variety of experiences of psychosis.

If I would like to help what will I have to do?

If you would like to take part all you would have to do would be for you and your relative to complete some questionnaires on a single occasion. The questionnaires should take about 20 minutes to half and hour to complete. Your relative can be a parent, brother, sister, spouse, and so on, - that will be your choice - but someone who has a lot of contact with you would probably be best.

If you wanted to take part, we would then need your permission to contact your relative and see if they would be willing to take part as well. We would choose a venue that

would be of least inconvenience to you. If you have to travel to a local NHS centre of your choice, Newtown Hospital for example, travelling expenses will be reimbursed at the public transport rate. You and your relative would meet with one of the research team and have an opportunity to ask any questions you may have before you agree to do anything. If you felt you wished to participate, we would then ask you and your relative to sign a consent form. By this you and your relative give your consent to participate in the study. Access may also be made to your medical records.

All information will be kept strictly confidential. Any information about you will be anonymised so that you cannot be recognised from it. Although you may have given your signed consent, you will of course be able to withdraw from the study at any time and without giving a reason.

If I do not want to take part what will happen then?

If you prefer not to take part, then you do not have to. The people involved in your care will not be upset if you decide not to take part. Whatever you decide to do will not in any way affect the treatment or standard of care you receive from your doctors or any other health care professional.

Thank you for taking the time to read this information leaflet.

Independent Advice for Participants of Research Studies in Worcestershire

If you would like independent advice about taking part in the study, you can contact the Community Health Council at:

- Burnage Lodge, 184 Franche Road, Kidderminster, DY11 1DA – telephone 01562 69243; or
- Red House, Church Green West, Redditch, B97 4BG – telephone: 01527 61375; or
- Severn House, 10 The Moors, Worcester, WR1 3EE – telephone: 01905 22715.

Appendix VII

Patients and Family Members Views About the Experience of Psychosis

An Information Sheet

What's the study about?

Caregivers and their relatives (family members) who have received a diagnosis of psychosis are likely to hold a wide range of views about their experiences. For example, some people may hold particular views about the causes or consequences of psychosis while other people may hold other views about these experiences. In a similar way, family members would also have views about the person's experiences. We are interested in hearing the ways in which you as a caregiver and your relative view his/her experiences and the impact they have on both your lives, as well as the kinds of things you do to cope with these experiences. Information obtained during the course of the study may help us to understand better the experiences of psychosis.

If I would like to help what will I have to do?

If you would like to take part all we ask is that:

- *You and your relative complete a questionnaire booklet each.*

The questionnaire should take about half and hour or so to complete. All responses on the questionnaire will be kept strictly confidential. All information will be anonymised and transformed into numbers for confidentiality.

If I do not want to take part what will happen then?

If you prefer not to take part for whatever reason, then you do not have to. If you do not wish to take part your decision will not in any way affect the treatment or standard of care your relative receives from his/her doctors or any other health care professional.

Thank you for taking the time to read this information leaflet.

Appendix VIII

Members of the General Public's Views About the Experience of Schizophrenia

An Information Sheet

You are being invited to take part in a research project. Here is some information to help you decide whether or not to take part. Please take time to read the following information carefully and discuss it with friends or relatives if you wish. Ask us if there is anything you do not understand or if you would like more information. Thank you for reading this information sheet.

What's the study about?

People have a wide range of views about schizophrenia. For example, some people may hold particular views about the causes or consequences of it while other people may hold other views about these experiences. We are interested in hearing your views about schizophrenia. Information obtained during this survey may help us to understand members of the public's views about schizophrenia.

If I would like to help what will I have to do?

If you would like to take part all we ask is that:

- *You complete a short anonymous questionnaire about your views of schizophrenia.*

The questionnaire should take about fifteen minutes or so to complete. All responses on the questionnaire will be kept strictly confidential. All information will be anonymised and transformed into numbers for confidentiality.

If I do not want to take part what will happen then?

If you prefer not to take part for whatever reason, then you do not have to.

Thank you for taking the time to read this information leaflet.

Appendix IX

Carer's Questionnaire

Your Views About Your Relative's Experiences

Name _____

Date of Birth _____

Relationship to patient _____
(i.e., father, mother, brother, sister, etc)

Age of relative _____

Number of Relapses _____

Age of relative when first diagnosed _____

Family Questionnaire

We are interested in finding out what problems, if any, you experience with your relative at home. We would also like to find out how much stress these problems cause you and how well you feel able to cope with the difficulties. We hope this information will be of use in helping relatives to overcome such problems.

Please read each statement below which describes a behaviour which may have occurred with your relative. If it has not occurred simply circle the '1' in the first column (How often) to indicate that this behaviour never happens. There is no need to mark the other two columns (Bother or control) in this case.

However if the behaviour does occur, please indicate how often it does so by circling one of the numbers. For example if your relative 'becomes irritable and easily upset' several times each week, then circle the '4' to show that this happens frequently. In much the same way, please indicate in the next two columns how much this behaviour bothers you, and how well or badly you feel able to cope with it at home.

<u>How often</u> does this happen?	**How much does this <u>Bother</u> you?**	**How well do you feel able to <u>Control and Cope</u> with this behaviour?**
1 = Never	1 = Never	1 = Never
2 = Rarely	2 = Rarely	2 = Rarely
3 = Sometimes	3 = Sometimes	3 = Sometimes
4 = Frequently	4 = Frequently	4 = Frequently
5 = Always	5 = Always	5 = Always

	How often	*Bother*	*Control*
1. Becomes restless (e.g., pacing about, not sitting through meals)	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
2. Complains of headaches or other pains	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
3. Is unpredictable or impulsive	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
4. Hits or hurts people	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
5. Gets noisy or shouts a lot	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
6. Is unusually fussy or finicky about things	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
7. Gets bored very easily	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
8. Gets jealous of other family members or friends	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
9. Lacks interest in friends and relatives	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
10. Is odd in appearance, manner or movement	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
11. Avoids meeting people	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5

How often does this happen?

1 = Never
2 = Rarely
3 = Sometimes
4 = Frequently
5 = Always

How much does this Bother you?

1 = Never
2 = Rarely
3 = Sometimes
4 = Frequently
5 = Always

How well do you feel able to Control and Cope with this behaviour?

1 = Never
2 = Rarely
3 = Sometimes
4 = Frequently
5 = Always

	How often	*Bother*	*Control*
12. Gets destructive or knocks things about in the house	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
13. Talks to himself/herself or imaginary companions	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
14. Wakes/gets up unusually early in the morning	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
15. Grumbles a lot	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
16. Sits or lies around not doing much	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
17. Thinks people are against him/her	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
18. Lacks concentration or attention	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
19. Slow at doing things	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
20. Stays out very late at night	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
21. Becomes irritable and easily upset	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
22. Is unclean or untidy	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
23. Spends long periods alone	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
24. Has marked difficulties with memory such as not being able to find his/her way home, difficulty remembering people's houses	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
25. Expresses odd ideas	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
26. Has unusual fears	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
27. Is unusually cheerful or excited	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
28. Talks or laughs to himself/herself	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
29. Says nothing when spoken to	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
30. Fritters away money	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
31. Abuses drugs	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
32. Drinks excessively	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5

How often does this happen?

1 = Never
2 = Rarely
3 = Sometimes
4 = Frequently
5 = Always

How much does this Bother you?

1 = Never
2 = Rarely
3 = Sometimes
4 = Frequently
5 = Always

How well do you feel able to Control and Cope with this behaviour?

1 = Never
2 = Rarely
3 = Sometimes
4 = Frequently
5 = Always

	How often	*Bother*	*Control*
33. Has difficulty in getting to sleep	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
34. Has unusual habits or routines	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
35. Has poor appetite/does not want to eat	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
36. Has routines of doing things only in a certain way	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
37. Keeps to himself/herself a lot	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
38. Accuses or threatens people	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
39. Has periods of panic or anxiety	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
40. Acts in a bizarre way	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
41. Has rows or quarrels	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
42. Worries a lot about things	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
43. Swears or is rude to people	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
44. Gets miserable or depressed	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
45. Pays insufficient towards keep	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
46. Talks nonsense when spoken to	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
47. Mixes with undesirable company	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
48. Refuses to take medication (tablets or injections)	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5

49. Any other problems not listed above?
(please specify below)

.....

IPQ-R

Your views about your relative's experiences

We are interested in your own personal views of how you see your relative's experiences/condition. Please indicate how much you agree or disagree with the following statements by ticking the appropriate box for each statement.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1. It will last a short time					
2. It is likely to be permanent rather than temporary					
3. It will last for a long time					
4. It will pass quickly					
5. I expect my relative to have these experiences for the rest of his/her life					
6. My relative's experiences are a serious matter					
7. It has had major consequences on his/her life					
8. It has not had much effect on his/her life					
9. It strongly affects the way others see him/her					
10. It has serious financial consequences					
11. It causes difficulties for those who are close to him/her					
12. There is a lot which my relative can do to control it					
13. What my relative does can determine whether it gets better or worse					
14. The course of my relative's condition/experiences depends on him/her					
15. Nothing my relative does will affect it					
16. My relative has the power to influence it					
17. My relative's actions will have no effect on the outcome of it					
18. It will improve in time					
19. There is very little that can be done to improve it					
20. My relative's treatments will be effective in curing it					

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
21. The negative effects of it can be prevented (avoided) by his/her treatment					
22. My relative's treatment can control it					
23. There is nothing which can help my relative's condition					
24. The symptoms of my relative's condition are puzzling to him/her					
25. My relative's experiences/condition are a mystery to him/her					
26. My relative doesn't understand his/her experiences/condition					
27. It doesn't make any sense to him/her					
28. My relative has a clear picture or understanding of it.					
29. It changes a great deal from day to day					
30. It comes and goes in cycles					
31. It is very unpredictable					
32. My relative goes through cycles in which it gets better and worse					
33. My relative gets depressed when he/she thinks about it					
34. When my relative thinks about it he/she gets upset					
35. It makes him/her feel angry					
36. It does not worry him/her					
37. It makes my relative feel anxious					
38. It makes him/her feel afraid					

CAUSES OF THESE EXPERIENCES

We are interested in what **you** consider may have been the cause of your relative's experiences/condition. As people are very different there is no correct answer for this question. We are most interested in **your own views** about the factors that caused it rather than what others including doctors or family members may have suggested to you. Below is a list of possible causes. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1. Stress or worry					
2. Hereditary – it runs in the family					
3. A germ or virus					
4. Diet or eating habits					
5. Chance or bad luck					
6. Poor medical care in the past					
7. Pollution in the environment					
8. It is largely due to his/her own behaviour					
9. My relative's mental attitude, (e.g., thinking about life negatively)					
10. Family problems or worries caused it					
11. Overwork					
12. My relative's emotional state (e.g., feeling down, lonely, anxious)					
13. Ageing					
14. Alcohol or other drugs					
15. Smoking					
16. Accident or injury					
17. My relative's personality					
18. Altered immunity					

In the table below please list in rank order the three most important factors that **you** now believe caused your relative'sexperiences/condition. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me are:

1. _____
2. _____
3. _____

These items below say something about a particular way of coping. Obviously, different people deal with things in different ways. I would like to know to what extent you've been using each of the different ways of coping below. How much or how frequently. Use the response choice boxes from 'not at all' to 'a lot' for each item. Tick whichever of the response choice boxes for each item that correspond to the things YOU do

		Not At All	A Little Bit	A Medium Amount	A Lot
1	I've been turning to work or other activities to take my mind off things.				
2	I've been concentrating my efforts on doing something about the situation I'm in,				
3	I've been saying to myself "this isn't real"				
4	I've been using alcohol or other drugs to make myself feel better				
5	I've been getting emotional support from others				
6	I've been giving up trying to deal with it.				
7	I've been taking action to try and make the situation better				
8	I've been refusing to believe that it has happened				
9	I've been saying things to let my unpleasant feelings escape				
10	I've been getting help and advice from other people				
11	I've been using alcohol or other drugs to help me get through it.				
12	I've been trying to see it in a different light, to make it seem more positive				
13	I've been criticizing myself				
14	I've been trying to come up with a strategy about what to do				
15	I've been getting comfort and understanding from someone				
16	I've been giving up the attempt to cope				
17	I've been looking for something good in what is happening.				
18	I've been making jokes about it.				
19	I've been doing something to think about it less, such as going to the movies, watching TV, reading, daydreaming, sleeping or shopping				
20	I've been accepting the reality of the fact that it has happened.				
21	I've been expressing my negative feelings				
22	I've been trying to find comfort in my religion or spiritual beliefs.				
23	I've been trying to get advice or help from other people about what to do.				
24	I've been learning to live with it.				
25	I've been thinking hard about what steps to take.				
26	I've been blaming myself for things that have happened.				
27	I've been praying or meditating				
28	I've been making fun of the situation.				

Hospital Anxiety and Depression Scale

This questionnaire is designed to see how you feel at present. Read each item and **underline** the reply which comes closest to how you have been feeling in the past week.

1. I feel tense or wound up:
Most of the time
A lot of the time
From time to time, occasionally
Not at all

2. I still enjoy the things I used to:
Definitely as much
Not quite so much
Only a little
Hardly at all

3. I get a sort of frightened feeling as if something awful is about to happen:
Very definitely and quite badly
Yes, but not too badly
A little, but it doesn't worry me
Not at all

4. I can laugh and see the funny side of things:
As much as I always could
Not quite so much now
Definitely not so much now
Not at all

5. Worrying thoughts go through my mind:
A great deal of the time
A lot of the time
From time to time but not too often
Only occasionally

6. I feel cheerful:
Not at all
Not often
Sometimes
Most of the time

7. I can sit at ease and feel relaxed:
Definitely
Usually
Not often
Not at all

8. I feel as if I am slowed down:
Nearly all the time
Very often
Sometimes
Not at all

9. I get a sort of frightened feeling like 'butterflies' in the stomach:
Not at all
Occasionally
Quite often
Very often

10. I have lost interest in my appearance:
Definitely
I don't take as much care as I should
I may not take quite as much care
I take just as much care as ever

11. I feel restless as if I have to be on the move:
Very much indeed
Quite a lot
Not very much
Not at all

12. I look forward with enjoyment to things:
As much as I ever did
Rather less than I used to
Definitely less than I used to
Hardly at all

13. I get sudden feelings of panic:
Very often indeed
Quite often
Not very often
Not at all

14. I can enjoy a good book or radio or TV:
Often
Sometimes
Not often
Very seldom

Appendix X

Patients Questionnaire

Your Views About Your Experiences

Name _____

Date of Birth _____

Age when first diagnosed _____

Your views about your experiences

Listed below are a number of statements that you may or may not have experienced since your diagnosis. Please indicate by circling *Yes* or *No*, whether you have experienced any of these statements, and whether you believe that these experiences are related to your illness.

	I have experienced this *since my diagnosis*		**This is *related*** *to my diagnosis*	
My expression remains the same whether I feel happy or sad	Yes	No	Yes	No
I lack expressive gestures	Yes	No	Yes	No
My speech is flatter	Yes	No	Yes	No
I lack spontaneous movements	Yes	No	Yes	No
My mood is lower	Yes	No	Yes	No
I have trouble making eye contact with people	Yes	No	Yes	No
I don't say much now	Yes	No	Yes	No
I don't pay much attention to what's happening around me	Yes	No	Yes	No
My responses are slower	Yes	No	Yes	No
My thoughts get jumbled up	Yes	No	Yes	No
My thoughts don't stay on one subject	Yes	No	Yes	No
People don't understand what I'm trying to say	Yes	No	Yes	No
Sometimes I think I'm someone else	Yes	No	Yes	No
Others are able to control my emotions	Yes	No	Yes	No
I have difficulties in relationships with my friends	Yes	No	Yes	No
I have difficulties in feeling intimacy and closeness	Yes	No	Yes	No
I take less interest in leisure activities	Yes	No	Yes	No
I take less interest in sex	Yes	No	Yes	No
Thoughts are placed in my mind by others	Yes	No	Yes	No

	I have experienced this *since my diagnosis*		**This is *related* to my diagnosis**	
My thoughts are transmitted so others know them	Yes	No	Yes	No
My thoughts are suddenly taken out of my mind	Yes	No	Yes	No
Others control my behaviour	Yes	No	Yes	No
Others can read my mind	Yes	No	Yes	No
I sometimes see, feel or hear things that others cannot	Yes	No	Yes	No
I hear voices commenting on my behaviour	Yes	No	Yes	No
I hear voices talking together	Yes	No	Yes	No
I feel lacking in energy	Yes	No	Yes	No

Any other experiences (please write them below)

	I have experienced this *since my diagnosis*		This is *related* to my diagnosis	
_____	Yes	No	Yes	No
_____	Yes	No	Yes	No
_____	Yes	No	Yes	No
_____	Yes	No	Yes	No
_____	Yes	No	Yes	No

IPQ-R

We are interested in your own personal views of how you see your experiences/condition. Please indicate how much you agree or disagree with the following statements about your experiences by ticking the appropriate box for each statement.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1.It will last a short time					
2. It is likely to be permanent rather than temporary					
3. It will last for a long time					
4. It will pass quickly					
5. I expect to have these experiences for the rest of my life					
6. It is a serious matter					
7. It has had major consequences on my life					
8. It has not had much effect on my life					
9. It strongly affects the way others see me					
10. It has serious financial consequences					
11. It causes difficulties for those who are close to me					
12. There is a lot which I can do to control it					
13. What I do can determine whether it gets better or worse					
14. The course of my condition/experiences depends on me					
15. Nothing I do will affect it					
16. I have the power to influence it					
17. My actions will have no effect on the outcome of it					
18. It will improve in time					
19. There is very little that can be done to improve it					
20. My treatments will be effective in curing my condition/experiences					
21. The negative effects of it can be prevented (avoided) by my treatment					

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
22. My treatment can control it					
23. There is nothing which can help it					
24. These experiences are puzzling to me					
25. It is a mystery to me					
26. I don't understand my experiences/condition					
27. It doesn't make any sense to me					
28. I have a clear picture or understanding of it					
29. It can change a great deal from day to day					
30. It comes and goes in cycles					
31. It is very unpredictable					
32. I go through cycles in which it gets better and worse					
33. I get depressed when I think about it					
34. When I think about it I get upset					
35. It makes me feel angry					
36. It does not worry me					
37. Having these experiences makes me feel anxious					
38. It makes me feel afraid					

CAUSES OF MY EXPERIENCES / CONDITION

We are interested in what **you** consider may have been the cause of your condition/experiences. As people are very different there is no correct answer for this question. We are most interested in **your own views** about the factors that caused **your** experiences/condition rather than what others including doctors or family members may have suggested to you. Below is a list of possible causes. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1. Stress or worry					
2. Hereditary – it runs in the family					
3. A germ or virus					
4. Diet or eating habits					
5. Chance or bad luck					
6. Poor medical care in the past					
7. Pollution in the environment					
8. It is largely due to my own behaviour					
9. My mental attitude, (e.g., thinking about life negatively)					
10. Family problems or worries caused my illness					
11. Overwork					
12. My emotional state (e.g., feeling down, lonely, anxious)					
13. Ageing					
14. Alcohol or other drugs					
15. Smoking					
16. Accident or injury					
17. My personality					
18. Altered immunity					

In the table below please list in rank order the three most important factors that **you** now believe caused your condition/experiences. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me are:

1. _____

2. _____

3. _____

Please rate how strongly you agree or disagree with each of the following statements by circling a number between 1 and 6 for each statement.

	Strongly Agree					**Strongly Disagree**
1. Most people would willingly accept a person who has been diagnosed with psychosis as a close friend.	1	2	3	4	5	6
2. Most people believe that a person with psychosis is just as intelligent as anyone else.	1	2	3	4	5	6
3. Most people believe that a person with psychosis is just as trustworthy as anyone else.	1	2	3	4	5	6
4. Most people would accept a fully recovered person with psychosis as a teacher in a school.	1	2	3	4	5	6
5. Most people believe that being diagnosed with psychosis is a sign of personal weakness.	1	2	3	4	5	6
6. Most people would not hire a former patient to take care of their children, even if he or she had been well for some time	1	2	3	4	5	6
7. Most people think less of a person who has been an inpatient in a psychiatric ward	1	2	3	4	5	6
8. Most employers will hire a former patient if he or she is qualified for the job.	1	2	3	4	5	6
9. Most employers will pass over the application of a person who has been treated for psychosis in favour of another applicant.	1	2	3	4	5	6
10. Most people in my community would treat a person who has been treated for psychosis just as they would treat anyone.	1	2	3	4	5	6
11. Most young women would be reluctant to date a man who has been treated for psychosis.	1	2	3	4	5	6
12. Once they know a person was diagnosed with schizophrenia, most people will take his or her opinions less seriously.	1	2	3	4	5	6
13. In order to get a job, a person who has been treated for psychosis will have to hide his or her history of this.	1	2	3	4	5	6
14. There is no reason for a person to hide the fact that he or she was treated for psychosis at one time.	1	2	3	4	5	6
15. If you have a serious mental illness, the best thing to do is to keep it a secret.	1	2	3	4	5	6

	Strongly Agree					Strongly Disagree
16. If I had a close relative who had been treated for psychosis, I would advise him or her not to tell anyone about it.	1	2	3	4	5	6
17. I rarely feel the need to hide the fact that I have been in psychiatric treatment.	1	2	3	4	5	6
18. I've found that it's best to help the people close to me understand what psychiatric treatment is like.	1	2	3	4	5	6
19. If I thought a friend was uncomfortable with me because I had been in psychiatric treatment, I would take it upon myself to educate him or her.	1	2	3	4	5	6
20. If I thought an employer felt uneasy hiring a person who had been in psychiatric treatment, I would try to make him or her understand that most ex-patients are good workers.	1	2	3	4	5	6
21. After I entered psychiatric treatment, I often found myself educating others about what it means to experience psychosis.	1	2	3	4	5	6
22. I would participate in an organised effort to teach the public more about psychiatric treatment and the problems of people who seek psychiatric help.	1	2	3	4	5	6
23. It is easier for me to be friendly with people who have been treated for a mental illness.	1	2	3	4	5	6
24. If I thought someone I knew held negative opinions about psychiatric patients, I would try to avoid him or her.	1	2	3	4	5	6
25. After being treated for psychosis it's a good idea to keep what you are thinking to yourself.	1	2	3	4	5	6
26. If I was looking for a job and received an application which asked about a history of psychiatric treatment, I wouldn't apply for the job.	1	2	3	4	5	6
27. If I thought an employer was reluctant to hire a person with a history of psychiatric treatment, I wouldn't apply for the job.	1	2	3	4	5	6
28. If I believed a person I knew thought less of me because I had been in psychiatric treatment, I would try to avoid him or her.	1	2	3	4	5	6
29. When I meet people for the first time, I make a special effort to keep the fact that I have been in psychiatric treatment to myself.	1	2	3	4	5	6

Appendix XI

General Public Questionnaire

Your Views About Schizophrenia

Are you…….. Male or Female? (please circle one)

How old are you……Age _____ yrs

Listed below are a number of symptoms and behaviours that people with schizophrenia may or may not have experienced since their diagnosis. Please indicate by circling *Yes* or *No*, whether you believe each of these statements are *experienced by people with schizophrenia* (the 1st yes no column), and whether you believe that each of them are *related to their diagnosis of schizophrenia* (the 2nd yes no column). Please try to provide an answer for each statement. We are looking only for your best guess.

	Do they commonly experience this?		*If yes, is it related to their diagnosis?*	
Their expression remains the same whether they feel happy or sad	Yes	No	Yes	No
They lack expressive gestures	Yes	No	Yes	No
Their speech is flat	Yes	No	Yes	No
They lack spontaneous movements	Yes	No	Yes	No
Their mood is low	Yes	No	Yes	No
They have violent rages	Yes	No	Yes	No
They have trouble making eye contact with people	Yes	No	Yes	No
They do not say much	Yes	No	Yes	No
They do not pay much attention to what's happening around them	Yes	No	Yes	No
Their responses are slower	Yes	No	Yes	No
Their thoughts get jumbled up	Yes	No	Yes	No
Their thoughts don't stay on one subject	Yes	No	Yes	No
I would have difficulty in understanding what they are trying to say	Yes	No	Yes	No
They are unpredictable	Yes	No	Yes	No
They sometimes believes they are someone else	Yes	No	Yes	No
They believe someone else controls their emotions	Yes	No	Yes	No
They have difficulty in relationships with friends etc.	Yes	No	Yes	No
They have difficulty in feeling intimacy and closeness	Yes	No	Yes	No
Have less interest in leisure activities	Yes	No	Yes	No

	Do they commonly experience this?		*If yes, is it related to their diagnosis?*	
They have less interest in sex	Yes	No	Yes	No
They have more interest in sex	Yes	No	Yes	No
They believe thoughts are placed in their mind by someone else	Yes	No	Yes	No
They believe their thoughts are transmitted so others know them	Yes	No	Yes	No
They believe their thoughts are suddenly taken out of their mind	Yes	No	Yes	No
They believes others control their Behaviour	Yes	No	Yes	No
They believe others can read their mind	Yes	No	Yes	No
Sometimes they see, feel or hear things that others cannot	Yes	No	Yes	No
They hear voices commenting on their behaviour	Yes	No	Yes	No
They hear voices talking together	Yes	No	Yes	No
They experience a lack of energy	Yes	No	Yes	No
They are dangerous	Yes	No	Yes	No

Do you think they might have any other experiences (if so, please write them below)

_____	Yes	No	Yes	No
_____	Yes	No	Yes	No
_____	Yes	No	Yes	No
_____	Yes	No	Yes	No

We are interested in your own personal views about schizophrenia. Please indicate how much you agree or disagree with the following statements by ticking the appropriate box for each statement. Please try to provide an answer for each statement. We are looking only for your best guess.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1. Schizophrenia lasts a short time					
2. It is likely to be permanent rather than temporary					
3. It will last for a long time					
4. It will pass quickly					
5. They can expect to have these experiences for the rest of their lives					
6. Schizophrenia is a serious matter					
7. It has major consequences on their lives					
8. It does not have much effect on their lives					
9. It strongly affects the way others see them					
10. It has serious financial consequences					
11. It causes difficulties for those who are close to them					
12. There is a lot which patients themselves can do to control it					
13. What patients themselves do can determine whether it gets better or worse					
14. The course of schizophrenia depends on them					
15. Nothing the patient does will affect it					
16. They have the power to influence it					
17. Their actions will have no effect on the outcome of it					
18. It will improve in time					
19. There is very little that can be done to improve it					
20. Current treatments will be effective in curing it					

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
21. The negative effects of it can be prevented (avoided) by treatment					
22. Their treatment can control it					
23. There is nothing which can help their condition					
24. The symptoms of the condition are puzzling to people who suffer from it					
25. Their experiences/condition are a mystery to them					
26. Patients do not understand their experiences/condition					
27. It doesn't make any sense to them					
28. Patients have a clear picture or understanding of it.					
29. It changes a great deal from day to day					
30. It comes and goes in cycles					
31. It is very unpredictable					
32. They go through cycles in which it gets better and worse					
33. They get depressed when they think about it					
34. When they think about it they get upset					
35. It makes them feel angry					
36. It does not worry them					
37. It makes patients feel anxious					
38. It makes patients feel afraid					

CAUSES OF SCHIZOPHRENIA

We are interested in what **you** consider may have been the cause of schizophrenia. As people are very different there is no correct answer for this question. We are most interested in **your own views** about the things you think may cause it, rather than what others may have suggested to you. Below is a list of things that may or may not be causes of schizophrenia. Please indicate how much you agree or disagree with each statement by ticking the appropriate box. Please try to provide an answer for each statement. We are looking only for your best guess.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1. Stress or worry causes it					
2. It's hereditary – it runs in the family					
3. A germ or virus is responsible					
4. Diet or eating habits					
5. Chance or bad luck					
6. Poor medical care in the past					
7. Pollution in the environment					
8. It is largely due to their own behaviour					
9. Their mental attitude, (e.g., thinking about life negatively)					
10. Family problems or worries cause it					
11. Overwork causes it					
12. Too little work causes it					
12. Their emotional state (e.g., feeling down, lonely, anxious)					
13. Their age					
14. Alcohol or other drugs					
15. Smoking					
16. Accident or injury to their brain					
17. Their personality					
18. Altered immunity					

In the table below please list in rank order (1= most important) the three most important factors that **you** now believe cause schizophrenia. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me are:

1. _____

2. _____

3. _____

Appendix 2

Instructions for Authors

Social Science and Medicine

Guide for Authors

Submission of Papers

Two types of contribution are welcomed: full papers (original research reports or critical reviews of a field, preferably in no more than 8000 words) and short items (short reports of research findings, commentaries on topical issues or correspondence, of no more than 2000 words in length).

Authors are requested to submit their original manuscript and figures with two copies to the Editor-in-Chief, Professor Sally Macintyre, MRC Social and Public Health Sciences Unit, 4 Lilybank Gardens, Glasgow G12 8RZ, UK; or to the relevant Senior Editor.

Submissions will be considered on the understanding that they comprise original, unpublished material and are not under consideration for publication elsewhere. A covering letter to this effect should be enclosed with each submission, signed by all authors of the paper. *Social Science & Medicine* does not normally list more than six authors to a paper, and special justification must be provided for doing so. Further information on criteria for authorship can be found in Macintyre (1997, Vol. 45(1), 1-2).

All submissions may be subject to initial assessment by the appropriate Senior Editor to determine their suitability for consideration by *Social Science & Medicine*. Papers accepted for formal review will be sent anonymously to at least two independent referees. Authors are requested to alert the Editors in cases where rapid publication is especially appropriate.

Manuscript Preparation

General: Manuscripts must be typewritten, double-spaced with wide margins, on one side of white paper. Good quality printouts with a font size of 12 or 10 pt are required. The corresponding author should be identified (include a fax number and e-mail address). Full postal addresses must be given for all co-authors. Authors should consult a recent issue of the journal for style if possible. An electronic copy of the paper should accompany the **final** version. The Editors reserve the right to adjust style to certain standards of uniformity. Authors should retain a copy of their manuscript since no responsibility can be accepted for damage or loss of papers. Original manuscripts and illustrations will be discarded one month after publication unless the Publisher is asked to return original material after use.

Abstract and keywords: An abstract of up to 300 words is to be supplied, followed by up to six keywords.

Text: Follow this order when typing manuscripts: on the covering page - author, affiliation, full postal address, telephone number, fax number and e-mail address, names and affiliations of co-authors should be clearly indicated. Please ensure that these details are printed on the cover page only, and do not appear on any other page of the manuscript. On the following pages - Abstract, Keywords, Main text, Acknowledgements (on a separate sheet also), References, Appendix, Figure captions and then Tables. Do not import Figures or Tables into the main text. The corresponding author should be identified with an asterisk and footnote. All other footnotes (except for table footnotes) should be identified with superscript Arabic numbers. Footnotes are to be listed separately at the end of the text and not at the bottom of each page.

References: All publications cited in the text should be presented in a list of references following the text of the manuscript. In the text refer to the author's name (without initials) and year of publication (e.g. "Since Peterson (1993) has shown that..." or "This is in the agreement with results obtained later (Kramer, 1994)"). For 2-6 authors all authors are to be listed at first citation, with "&" separating the last two authors, for more than six authors, use the first six authors followed by et al. In subsequent citations for three or more authors use et al. in the text. The list of references should be arranged alphabetically by authors' names. The manuscript should be carefully checked to ensure that the spelling of authors' names and dates are exactly the same in the text as in the reference list. References should be given in the following form:

Williams, S., & Calnan, M. (1996). *Modern medicine: Lay perspectives and experiences*. London: UCL Press

Wethington, E., & Kessler, R.C. (1991). Situations and processes of coping. In J. Eckenrode (Ed.), *The social context of coping* (pp.13-29). New York: Plenum Press.

Kanani, S., (1998). Towards quality of care in child health programmes: A challenge for the partnership in health and social sciences. *Social Science & Medicine 47* (9), 1223-1230.

Illustrations: All illustrations should be provided in camera-ready form, suitable for reproduction (which may include reduction) without retouching. Photographs, charts and diagrams are all to be referred to as "Figure(s)" and should be numbered consecutively in the order to which they are referred. They should

accompany the manuscript, but should not be included within the text. All illustrations should be clearly marked on the back with the figure number and the author's name. All figures are to have a caption. Captions should be supplied on a separate sheet.
Line drawings: Good quality printouts on white paper produced in black ink are required. All lettering, graph lines and points on graphs should be sufficiently large and bold to permit reproduction when the diagram has been reduced to a size suitable for inclusion in the journal. Dye-line prints or photocopies are not suitable for reproduction. Do not use any type of shading on computer-generated illustrations.
Photographs: Original photographs must be supplied as they are to be reproduced. If necessary, a scale should be marked on the photograph. Please note that photocopies of photographs are not acceptable.
Colour: Where colour figures are required the author will be charged at the current colour printing costs. In cases where colour is paid for, authors will receive an additional one hundred offprints free of charge.
Tables: Tables should be numbered consecutively and given a suitable caption and each table typed on a separate sheet. Footnotes to tables should be typed below the table and should be referred to by superscript lowercase letters. No vertical rules should be used. Tables should not duplicate results presented elsewhere in the manuscript, (e.g. in graphs).

Electronic submission

Authors should submit an electronic copy of their paper with the final version of the manuscript. The electronic copy should match the hardcopy exactly. Always keep a backup copy of the electronic file for reference and safety. Full details of electronic submission and formats can be obtained from http://www.elsevier.nl/locate/disksub or from Author Services at Elsevier Science.

Proofs

Proofs will be sent to the author (first-named author if no corresponding author is identified of multi-authored papers) and should be returned within 48 hours of receipt. Corrections should be restricted to typesetting errors; any others may be charged to the author. Any queries should be answered in full. Please note that authors are urged to check their proofs carefully before return, since the inclusion of late corrections cannot be guaranteed. Proofs are to be returned to the Log-in Department, Elsevier Science, Stover Court, Bampfylde Street, Exeter, Devon EX1 2AH, UK.

Offprints

Twenty-five offprints will be supplied free of charge. Additional offprints and copies of the issue can be ordered at a specially reduced rate using the order form sent to the corresponding author after the manuscript has been accepted. Orders for reprints (produced after publication of an article) will incur a 50% surcharge.

Copyright

All authors must sign the "Transfer of Copyright" agreement before the article can be published. This transfer agreement enables Elsevier Science Ltd to protect the copyrighted material for the authors, without the author relinquishing his/her proprietary rights. The copyright transfer covers the exclusive rights to reproduce and distribute the article, including reprints, photographic reproductions, microfilm or any other reproductions of a similar nature, and translations. It also includes the right to adapt the article for use in conjunction with computer systems and programs, including reproduction or publication in machine-readable form and incorporation in retrieval systems. Authors are responsible for obtaining from the copyright holder permission to reproduce any material for which copyright already exists.
Author enquiries
Authors can keep track on the progress of their accepted article, and set up e-mail alerts informing them of changes to their manuscript's status, by using the "Track a Paper" feature of Elsevier's Author Gateway. Please visit http://authors.elsevier.com
Full details of electronic submission and formats can also be obtained from http://authors.elsevier.com
Contact details for questions arising after acceptance of an article, especially those relating to proofs, are provided when an article is accepted for publication

Journal of Clinical Psychology

Manuscript Submission

Please submit FOUR originals (including all illustrations and tables) of manuscripts for consideration to the editor, Larry E. Beutler, Ph.D. at the following address:
Journal of Clinical Psychology
Department of Education
Counseling/Clinical/School Psychology Program
University of California
Santa Barbara, CA 93106

All *In Session* articles are published by invitation only. Individuals interested in nominating, organizing, or guest editing an issue are encouraged to contact the editor-in-chief:
John C. Norcross, Ph.D.
Department of Psychology
University of Scranton
Scranton, PA 18510-4596
E-mail: norcross@uofs.edu

Manuscript Preparation

Format. Final manuscripts should be typed (or laser-printed) double-spaced with a 1" margin on all sides. Please use good quality white bond 8½ × 11 paper. Number all pages of the manuscript sequentially. Manuscripts should contain each of the following elements in sequence: 1) Title page 2) Abstract 3) Text 4) Acknowledgments 5) References 6) Tables 7) Figures 8) Figure Legends 9) Permissions. Start each element on a new page. Because the ***Journal of Clinical Psychology*** utilizes an anonymous peer-review process, authors' names and affiliations should appear ONLY on the title page of the manuscript.
Style. Please follow the stylistic guidelines detailed in the *Publication Manual of the American Psychological Association, Fourth Edition*, available from the American Psychological Association, Washington, D.C. *Webster's New World Dictionary of American English, 3rd College Edition*, is the accepted source for spelling. Define unusual abbreviations at the first mention in the text. The text should be written in a uniform style, and its contents as submitted for consideration should be deemed by the author to be final and suitable for publication.
Title Page. The title page should contain the complete title of the manuscript, names and affiliations of all authors, institution(s) at which the work was performed, and name, address, telephone and telefax numbers of the author responsible for correspondence. Authors should also provide a short title of not more than 45 characters (including spaces), and five to ten key words, that will highlight the subject matter of the article.
Abstract. Abstracts are required for research articles; dissertations in brief; and notes from the field. Abstracts must be 150 words or less, and should be intelligible without reference to the text.
Permissions. Reproduction of an unaltered figure, table, or block of text from any non-federal government publication requires permission from the copyright holder. All direct quotations should have a source and page citation. Acknowledgment of source material cannot substitute for written permission. It is the author's responsibility to obtain such written permission from the owner of the rights to this material.
Final Revised Manuscript. A final version of your accepted manuscript should be submitted on diskette as well as hard copy, using the Diskette Submission Instructions form included in most issues of the journal.

Article Types

- **Research Reports**. Research reports may include quantitative or qualitative investigations, or single-case research. They should contain Introduction, Methods, Results, Discussion, and Conclusion sections conforming to standard scientific reporting style (where appropriate, Results and Discussion may be combined).
- **Review Articles**. Review articles should focus on the clinical implications of theoretical perspectives, diagnostic approaches, or innovative strategies for assessment or treatment. Articles should provide a critical review and interpretation of the literature. Although subdivisions (e.g.

introduction, methods, results) are not required, the text should flow smoothly, and be divided logically by topical headings.

- **Dissertations in Brief**. The journal encourages the submission of important work by young investigators and researcher/practitioners. This section of the journal spotlights innovative research conducted during the student's graduate studies. Dissertations in Brief should contain an abstract, and provide a concise synopsis (10 manuscript pages or less) of the major findings presented in the student's final dissertation. The format of manuscripts submitted for this section may adhere to the Research Report or Review Article format as appropriate.
- **Notes from the Field**. Notes from the Field offers a forum for brief descriptions of advances in clinical training; innovative treatment methods or community based initiatives; developments in service delivery; or the presentation of data from research projects which have progressed to a point where preliminary observations should be disseminated (e.g., pilot studies; significant findings in need of replication). Articles submitted for this section should be limited to a maximum of 10 manuscript pages, and contain logical topical subheadings.
- **News and Notes**. This section offers a vehicle for readers to stay abreast of major awards, grants, training initiatives; research projects; and conferences in clinical psychology. Items for this section should be summarized in 200 words or less. The Editors reserve the right to determine which News and Notes submissions are appropriate for inclusion in the journal.

Editorial Policy

Manuscripts for consideration by the ***Journal of Clinical Psychology*** must be submitted solely to this journal, and may not have been published in another publication of any type, professional or lay. This policy covers both duplicate and fragmented (piecemeal) publication. Although, on occasion it may be appropriate to publish several reports referring to the same data base, authors should inform the editors at the time of submission about all previously published or submitted reports stemming from the data set, so that the editors can judge if the article represents a new contribution. If the article is accepted for publication in the ***Journal***, the article must include a citation to all reports using the same data and methods or the same sample. Upon acceptance of a manuscript for publication, the corresponding author will be required to sign an agreement transferring copyright to the Publisher; copies of the Copyright Transfer form are available from the editorial office. All accepted manuscripts become the property of the Publisher. No material published in the ***Journal*** may be reproduced or published elsewhere without written permission from the Publisher, who reserves copyright.

Any possible conflict of interest, financial or otherwise, related to the submitted work must be clearly indicated in the manuscript and in a cover letter accompanying the submission. Research performed on human participants must be accompanied by a statement of compliance with the Code of Ethics of the World Medical Association (Declaration of Helsinki) and the standards established by the author's Institutional Review Board and granting agency. Informed consent statements, if applicable, should be included with the manuscript stating that informed consent was obtained from the research participants after the nature of the experimental procedures was explained.

The ***Journal of Clinical Psychology requires*** that all identifying details regarding the client(s)/ patient(s), including, but not limited to name, age, race, occupation, and place of residence be altered to prevent recognition. By signing the *Copyright Transfer Agreement*, you acknowledge that you have altered all identifying details, or obtained all necessary written releases.

All statements in, or omissions from, published manuscripts are the responsibility of authors, who will be asked to review proofs prior to publication. Reprint order forms will be sent with the page proofs. No page charges will be levied against authors or their institutions for publication in the journal. Authors should retain copies of their manuscripts; the journal will not be responsible for loss of manuscripts at any time.